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FOREWORD

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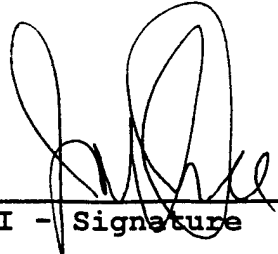

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Table of Contents:

Front Cover	1
Standard Form (SF) 298	2
Foreword	3
Table of Contents	4
Introduction	5
Body	6
Conclusions	30
References	34
<u>Appendices:</u>	36
Appendix A: Copies of Manuscripts in Press	
Appendix B: Copies of Measures Used in this Study	

INTRODUCTION

This project involves a prospective study of women who are at high risk for early-onset breast cancer and their families. The project tracked four interrelated groups: (1) approximately 500 proband women who have a risk for early onset breast cancer based on two or more family members being affected by cancer, and who will be among the first persons to have access to testing for alterations of the BRCA1 and BRCA2 genes; (2) the spouses of the approximately 400 women who are married; (3) a stratified random sampling of 120 of the women's unaffected sisters (those who have not been diagnosed with breast cancer); and (4) 80 brothers. Key variables include proband women and family members' stress and social support processes, including cancer-related stress and support; psychological distress and psychiatric morbidity; marital and family functioning; psychological characteristics presumed to affect the women's information-processing, decision-making, and subsequent adjustment; the at-risk women's intentions to seek predictive testing and anticipated outcomes and plans for use of the information; relevant attitudes, beliefs, and expectations; and current surveillance and adherence behaviors. Initial assessment of the proband women is by self-report questionnaires and telephone interviews. Subsequent reassessments of proband women's current cancer-related stress, support and beliefs, attitudes and intentions, distress, and psychiatric morbidity will also be by telephone interview and questionnaire. Husbands and siblings are assessed by self-report questionnaires. The proband women, spouses and siblings are then reassessed as the option of predictive testing is made available to the individual women. A second reassessment of proband women occurs 8 weeks after test results are available. Follow-up assessments occur at 6 and 12 months for women choosing to receive their genetic testing results, and yearly for women whose test results are not yet available. The main objectives of the study have been to describe psychological distress and psychiatric morbidity among high-risk women and their families, to evaluate the performance of screening instruments in detecting clinical depression, to describe social support processes among high-risk women, and as follow-up data become available, to assess the impact of genetic testing on women and their families.

BODY

Background

Predictive testing is now available for mutations of both the BRCA1 and BRCA2 genes, known to increase risk for breast and ovarian cancer, and possibly other forms of cancer as well (e.g., prostate). Only about 5-10% of all breast cancer is believed to be hereditary in nature, but this figure could be as high as 20% for early onset breast cancer. Furthermore, it has been estimated that 15-45% of all families with multiple cases of breast cancer and as much as 80% of families with elevated rates of both early-onset breast and ovarian cancer carry mutations of either BRCA1 or BRCA2, although these figures may be somewhat lower in the general population than in the hereditary breast and ovarian cancer registries from which they were derived.

It has also been estimated that female carriers of mutations in BRCA1 or BRCA2 have a 50-85% lifetime risk of developing breast cancer. Carriers of BRCA1 mutations have a 20-40% lifetime risk of developing ovarian cancer, while the risk associated with BRCA2 is slightly lower at 15-20%. Male carriers of these altered genes are at somewhat increased risk for prostate and colon cancer, and male carriers of BRCA2 have a 6% risk of breast cancer. Cancer susceptibility conferred by BRCA1 and BRCA2 mutations is transmitted as an autosomal dominant trait which means that the mutations are inherited from either parent, and offspring have a 50% risk of inheriting the parental mutation. Options for women who test positive for an altered gene related to breast cancer include increased surveillance, prophylactic mastectomy and oophorectomy, and for some, participation in a chemo-prevention trial. None of these measures have proven to be entirely efficacious and all have known limitations, as recently noted by our investigator group (Eisen & Weber, 1999).

The current project has been tracking women and their families from well-before genetic testing occurs up to 12 months after receipt of genetic test results. Testing has been offered to our research sample of high-risk women as part of a series of genetic linkage and mutation studies, and it has now also become available in the community. It is now estimated that approximately 1 in 1,000 people are carriers of mutations of these genes (Ford & Easton, 1995), and larger numbers can be expected to face the dilemma of whether to seek testing. Mutations of these genes are the first for which widespread genetic screening of asymptomatic persons for risk of late onset disease is appropriate, and the availability of the test raises some daunting and largely unprecedented issues. Women with positive family histories of breast cancer have expressed considerable interest in obtaining predictive testing. Yet little is known about the extent to which women who indicate they intend to obtain testing actually follow through with it. Furthermore, little was known about the anticipated benefits and drawbacks of knowledge of risk status which would influence their choice, or about the psychological and social costs to these women and their families of having access to such information. Positive findings could conceivably carry the threat of psychological

and psychiatric morbidity for the women and family members, the disruption of family relationships, and the impairment of the women's surveillance and adherence behavior, but the degree of vulnerability and factors which identify the individuals and families at greatest vulnerability have not yet been determined. Yet, negative findings or not obtaining information concerning risk status could also have detrimental effects on the women and their families.

In the absence of a large body of directly relevant prior research, we were faced with an urgent need for basic descriptive data concerning women at high risk for early onset breast cancer and their families, including their psychosocial assets and liabilities, their attitudes and beliefs, their intention to seek predictive testing, and their preparedness for possible results. We have now collected a substantial body of descriptive data about women with family histories of cancer, and their experiences with genetic testing, and have been disseminating these data (Coyne & Anderson, in press; Coyne, Benazon, Gaba, Calzone, & Weber, in press).

Recognizing the opportunity to build on our extensive baseline assessment with prospective data, we also instituted follow-up assessments at key points in the process of genetic testing. Now that the project has progressed to its third year, we are accumulating substantial follow-up data that allows us to track changes over time in participants' psychological and social functioning, cancer-specific perceptions and health behaviors, and other relevant factors. Our follow-up assessments also allow for describing how participants view the process of genetic testing, and the role that genetic testing has played in participants' lives. Furthermore, we have developed collaborative arrangements to ensure the predictive utility of our data in examining the long-term consequences of high-risk status and the availability of genetic screening to these women.

This project is a longitudinal study of a large sample of high-risk women and their family members who are among the first being offered the option of testing for BRCA1 and BRCA2. We originally anticipated assessing approximately 300 high-risk women, but have been able to expand recruitment to almost 500 women, due to the expansion of the Hereditary Breast and Ovarian Cancer registry. Women participating in our study receive in-depth baseline assessment by questionnaire and telephone interview. Initial assessments were started at the point of receipt of funding from the DoD. We sought additional funding through the Department of Defense Breast Cancer Initiative in order to complete initial assessments and to monitor women's progression through the process of genetic testing. We originally instituted assessments at 4 time points: when testing for BRCA1 becomes available to the individual women, within 8 weeks after receipt of results, and 6 and 12 months after testing.

Our sample is well described in terms of medical and family history. Our assessment instruments are psychosocial measures with immediate relevance to planning and the design of clinical protocols, as well as for their use in clarifying basic individual and family stress and coping processes. Variables assessed included attitudes and beliefs; personality traits; social support and

family functioning; psychological distress and psychiatric morbidity; and decisions and behavior relevant to management of cancer risk. These measures will also allow estimation of psychosocial costs, if any, associated with the offering of testing, and modeling of intention to obtain testing and subsequent decision-making and functioning. The resulting longitudinal data will have a direct application in estimating the need for services, refining appropriate clinical protocols, and suggesting requisite training for personnel providing services.

Additionally, given the importance of a woman's social support system, and the recognition that testing may be an event for husbands and family as well, this project incorporated a protocol for assessments of the husbands and siblings of participating women. Husbands and siblings are assessed by questionnaire before the proband woman receives her results, and are reassessed at 6 months following the woman's receipt of results.

The first overall objective of this study has been to assess psychological distress, current and past psychiatric disorder, and functional impairment in women at high-risk for breast and ovarian cancer who are anticipating the prospect of genetic testing. Establishing base rates of distress and impairment permits us to evaluate the mental health needs of women anticipating testing, and it also serves as a first step in evaluating the incremental distress associated with receipt of results.

The second objective has been to compare the two groups of women within our sample: women who had been previously diagnosed with breast cancer, and women who had not been affected at the time of assessment. Initial differences between the two groups are important for the evaluation of the extent to which unaffected women subsequently develop characteristics like those of affected women upon receipt of findings that they carry the altered gene. On the other hand, it might prove to be the case that heightened awareness of high risk status among unaffected women has already resulted in comparable levels of distress and disorder.

A third objective has been to describe social support processes in the experiences of women at high risk for cancer and their families. This objective will continue as the women progress from baseline assessment through the opportunity to obtain results, and beyond testing to follow up periods. We have been particularly interested in the involvement of husbands and female family members in proband women's decision making concerning cancer risk management and whether to get testing. Spouses are usually the most important source of support for married persons (Brown & Harris, 1978; Coyne & DeLongis, 1986). Yet, the women in our study are members of high risk families, with first-degree female relatives in similar predicaments. The support and information that close female relatives provide, how these relatives cope with their own dilemmas, and the decisions about testing they make are likely to have profound effects on the high-risk women. It may be that as a result of the mobilization of social support around the shared risk of cancer, female relatives come to have more influence on the distress levels of these women, and the spouses correspondingly less. An understanding of these support processes has a practical

importance in the design of educational, counseling, and follow-up protocols for these women and their families.

A fourth, overarching objective has been to track psychosocial changes among participants through the process of genetic testing being offered to them. As a result of our ongoing assessment efforts, we anticipate having sufficient follow-up data in the near future to conduct initial longitudinal analyses, both for proband women and for their husbands (where applicable) and their sisters. These analyses can begin to evaluate changes with time in psychological distress, breast cancer worry and worry-related functional impairment, risk perception, screening behaviors, and other relevant factors. We also have rich descriptive follow-up data about the impact of genetic testing on the lives of high-risk women and their families.

Procedure and Accomplishments to Date

Years 1 & 2

As reported in two previous annual reports, we have successfully met our objectives during the first two years of the study. Expansion of the Hereditary Breast and Ovarian Cancer Registry from which subjects are drawn allowed recruitment of a larger sample for baseline assessment than previously expected. This was fortuitous because preliminary testing of blood samples from women already affected by breast and ovarian cancer in high risk families has now revealed that BRCA1 and BRCA2 account for less of the ostensibly hereditary breast cancer than previously predicted. At the present time, negative test results are generally not informative for women from families without a known mutation of BRCA1 or BRCA2. Identification of a particular mutation in a family member affected by breast cancer is a prerequisite for informative testing of unaffected family members. The implications of this are that many of the female family members of women in our sample will not be offered testing unless a mutation can be identified in our study participants. As noted below, there may also be an increased psychological burden on affected women seeking testing: Whether family members can be tested will depend on their results. Our now substantially augmented sample allows us to nonetheless have a more than adequate sample size and statistical power for women who do progress to a choice about testing.

We began to encounter delays during the second year in the offering of testing to individual women for a variety of technical and practical reasons. In response to these initial delays, and in anticipation of further delays, we designed an interim assessment to be administered if testing had not occurred within 1 year of baseline assessment. This interim assessment also served to reduce the burden of the baseline assessment by redistributing some of our trait measures to a second testing and it also involved the re-administration of measures of distress and other state variables likely to fluctuate over such a time period. As planned, women who progressed to the opportunity to get their results received these measures in their pre-counseling assessment. We also are taking advantage of a larger long-term follow-up study that will be recruiting women from the Hereditary

Breast and Ovarian Cancer Registry who are found to have a mutation of BRCA1 or BRCA2. Additionally, an international sample of persons, both male and female, who have been found to have a mutation is being recruited and tracked over the long-term. Although the long-term Follow-up study was originally designed to track morbidity and mortality, we have added a psychosocial component using instrumentation developed in our present project. Furthermore, for women from our present sample who will continue to be followed, we will have the benefit of data collection started before they were found to be carriers of a mutation. For some purposes they will be separated for data analysis, but for other purposes they can be combined. This addition will very likely make our sample the largest data base concerning persons who have received genetic testing for risk of breast and ovarian cancer.

We continued to make progress in our second year. We continued data collection, refined our research objectives, and modified our instrumentation based on initial results. Our interim assessment allowed us to monitor state variables such as mood, and to obtain additional trait measures for women having more than a year elapse between initial assessments and actually being offered testing. We also responded proactively to a number of exigencies, including a lower uptake of genetic testing than anticipated and a greater proportion of noninformative results among women who obtain testing, but at a slower rate than had been planned. We enrolled additional participants in the study as new women were recruited to the larger Hereditary Breast and Ovarian Cancer Registry. As anticipated, women who were already enrolled in our sample are continuing to receive the opportunity to obtain testing. Some progressed to 6-month follow up during the second year. Based on initial results, we adapted instrumentation to better accommodate women who receive uninformative results.

For example, we refined our assessments of women's appraisals of the opportunity to obtain testing. Our scaling technique for this is an important methodological innovation in itself. We also have taken advantage of our interim assessment of the women in our sample and the initial assessment of their husbands to explore the role of social support processes in the apparent resiliency of these women. One hypothesis is that explicit awareness of the high-risk status of these families has led to the mobilization of support processes organized around this status. If this is so, women in the community seeking testing may not share this advantage. This should prove to be one of the many valuable points of comparison between our registry and community samples.

Year 3

During the third year of the project, we have continued to track women through the process of genetic testing, with some women now progressing to 12-month follow-up. Our recruitment and assessment of spouses and sisters has proceeded on schedule. We also submitted several manuscripts which have now been accepted for publication, focusing on psychological distress (Coyne, Benazon, Gaba, Calzone, & Weber, in press), and social support (Coyne & Anderson, in

press). Copies of these manuscripts are included as Appendix A. We are in the process of analyzing data in preparation for a number of other manuscripts. One such manuscript expands upon the data presented in Coyne & Anderson, testing relationships between social support processes and psychological distress, and making use of the longitudinal data collected in this study. This project provides a unique opportunity to study the causal relationships among variables over time, as opposed to the majority of studies that are limited to making causal inferences from cross-sectional data. As more follow-up data become available, we intend to use causal modeling to clarify the temporal relationship between support and distress. Another set of analyses planned for publication involves describing perception of risk among women with a family history of cancer, and explaining how risk perception is formed and perhaps changed through the process of genetic testing. In a related study, we also plan to investigate the impact of genetic testing resulting in uninformative test results. Classic theory on predictive judgements (Rottenstreich & Tversky, 1977), the effects of framing on judgements (van Schie & van der Pligt, 1995), and preliminary data from the current study suggest that there may actually be a psychological cost of participating in genetic testing when results turn out to be uninformative. With the imminent release of a new batch of test results, we expect to be able to address this question.

In addition to the continued progress we have made in collecting and presenting data, we successfully responded to important structural and technical challenges, and created opportunities from these challenges that were previously not available to us. The key structural change this year was the transfer of the project from the University of Michigan to the University of Pennsylvania. Until this year, the research teams at the two institutions had been collaborating from a distance, with the biomedical research team located in Philadelphia, Pennsylvania, and the psychosocial research team located in Ann Arbor, Michigan. Shifting the psychosocial component of the project to Philadelphia has allowed for an integration of these two important and complementary aspects of genetic testing, and has generated a number of collaborative research projects that take advantage of the diverse areas of expertise of research team members, and substantially increase the utility of data we have been collecting from our registry sample.

One such project addresses the issues of selection bias and sample representativeness in the Hereditary Breast and Ovarian Cancer registry sample. One would expect that women who volunteer to participate in a cutting-edge research project such as this might be an especially motivated, persistent, well-adjusted, and socially-supported group. Indeed our data show that women in the registry sample are remarkably free of psychological distress and psychiatric morbidity, and were socially advantaged in terms of education, income, and marital stability. This is consistent with other reports of high-risk women in research and clinical protocols, and of research participants during the identification of genetic markers for Huntington's disease. Although highly-select registry samples have been well described, we know virtually nothing

about women in the general community who are in the process of seeking genetic testing. With increasing media attention, the continued research into genetic markers for cancer risk, and the promise of potentially modifying cancer risk, more women from the general population may seek or be offered genetic testing. Together with an oncologist extensively trained in epidemiology and biostatistics, we are in the process of implementing a large-scale study comparing the unique women in our research sample with two groups of women from the community. One group will come from an NCI Program Project studying women in the community (Brian Strom, Principal Investigator). In addition to capturing the experiences of women outside the highly-select registry sample, this project aims to describe the cancer risk experiences among African-American women who remain under-represented in the cancer registries.

Also, we are fulfilling our expectation for collaboration with University of Pennsylvania physicians, and recruiting a second group of women at high risk for cancer through the Cancer Risk Evaluation Program (CREP). Psychosocial and biomedical data from this study will allow comparisons between the cancer risk experiences of women in our registry sample and women seeking clinical (rather than research) services through the CREP.

Another project that developed as a result of our move to the University of Pennsylvania involves linking our psychosocial data with biomedical and other data for women participating in a randomized clinical trial of different methods of delivering genetic testing results. This project compares pre-test counseling and results disclosure by telephone with counseling and results disclosure conducted in-person at the physician's office. This study was instituted to address the inevitable changes in the genetic testing process as it moves from the controlled research setting to the larger community. This study aims to track the feasibility, acceptability, and effectiveness of different methods of delivering genetic testing services. Data from this new study will link with the extensive baseline psychosocial data already collected as part of the present study. This linking of data gives us the opportunity to test an aptitude-by-treatment interaction model (ATI), whereby specific participant characteristics are matched with particular types of interventions to achieve optimum effectiveness of services.

We are also expanding our Long-Term Follow-Up Study (LTF), begun last year as an adjunct to the current study. The LTF Study describes the long-term psychosocial functioning among women and men who have received genetic testing results through mechanism other than the University of Pennsylvania program.

Technical obstacles that began in the second year continued through the third year, resulting in delays in the actual availability of genetic testing results. Consultation with the University of Pennsylvania biomedical team suggests that the slow pace has been due in part to changing genetic testing technology. Specifically, laboratory technicians began to re-run assays to include an expanded range of exons, and began running southern blot assays on samples from families with

low probability of mutations. We have been in close communication with the laboratory technicians and testing coordinator regarding these delays. The team now anticipates a flood of requests for test results as these new testing procedures are completed within the next 4-6 months, and as women are notified that their test results are available. The net results is that there will be a significant increase in the number of women receiving results during the fourth year, adding to our rich database of follow-up assessments. Our move to Pennsylvania will allow us the close collaboration required to manage such a large increase in patient flow. In the meantime, we continue to describe the experiences of women who have not yet received results through yearly interim assessments.

In addition to technological challenges, it also became clear during the second and third years of the current study that women who had initially expressed interest in testing are requesting their results at a much lower rate than anticipated. The decision to accept testing is not a simple dichotomous one, with many women either failing to respond to the opportunity for testing, or deferring a decision to an unspecified later date. Some of this declining of testing is passive, with participants simply not responding to letters notifying them that their results are now available, or by their not returning consent forms. This is quite consistent with past experience with testing of persons at risk for Huntington's disease, but it remains an important phenomenon to study. Another investigator group has concluded that members of high risk families who decline testing in may suffer adverse psychological consequences (Lerman et al., 1997). However, we have shown that declining testing may represent a rational decision to defer testing when other stressors are present in women's lives (Coyne, Weber, & Sonis, in press). We are currently refining a project that addresses such issues, and will specifically assess the experiences of women who have been offered testing but have not pursued receipt of their results. Our initial data provides us the opportunity to explore predictors of discrepancies between initial intention to obtain testing and actually pursuing receipt of test results.

Methods

Women and their families participating in this study were drawn from the Hereditary Breast and Ovarian Cancer Registry originally established at the University of Michigan, but now housed at the University of Pennsylvania. There were two sets of criteria by which women could be included in the registry. Unaffected women had to have at least two cases of either breast or ovarian cancer in their family, and affected women had to have at least one other family member who had been affected. A periodic informational letter to women enrolled in the registry made reference to the possibility of an impending longitudinal study of them and family members. To recruit subjects for the psychosocial component of the University of Michigan/ University of Pennsylvania study, a cover letter, consent form, and questionnaire were sent to eligible enrollees in the registry. After the baseline questionnaire and consent form were returned, subjects were contacted by telephone in order to answer any questions and schedule the telephone interview. If we received neither a questionnaire nor a mail-back refusal form, we called subjects, explained the details of the study, and offered to send another packet if necessary. At the point of actual receipt of funding, some of the women had already participated in the initial assessment and had been alerted to the possibility of their being asked to continue in a longitudinal study and to enlist family members. Women continuing to participate in the study are asked to solicit the involvement of spouses. Given the sensitive nature of risk information, concerns about confidentiality dictated that we utilize the women rather than contact the family members directly. We discussed the rationale with the women for their family members' involvement, underscored the voluntary nature of their choice whether to facilitate their family members' participation in the study, and if they so chose, ask them to provide names and permission to contact these relatives.

Consistent with the previous years' reports, our ability to track women and their families through the course of their being offered testing has been partially dependent upon them actually being given the opportunity to obtain results, and on their pursuing receipt of results. A number of factors affected the offering of testing in general and to specific individuals. Actual testing has proceeded slowly in our sample, and is almost entirely limited to affected individuals or to women in families with known mutations. As mentioned above, we anticipate a significant increase in the pace of disclosure of results during the fourth year, now that improvements in laboratory procedures for genetic testing have been incorporated into standard practice.

The nature of testing for genetic mutations on BRCA1 and BRCA2 is difficult, and the current study will allow us to describe psychosocial implications of the process of genetic testing for high-risk women and their families. Because the two genes are very large, analyses of these entire genes would be impractically labor intensive and expensive. Therefore, at the present time, the accuracy and informativeness of testing is hinged upon whether there is a known mutation of BRCA1 or BRCA2 identified in an individual in the family affected with either breast or ovarian

cancer. When a known mutation is detected in a family, other members of that family can be tested specifically for that mutation, and testing results are informative (i.e., either positive or negative for the known mutation). If no such mutation has been identified in a particular family, then the only informative result for individual family members is when a specific mutation of BRCA1 or BRCA2 is identified. In the absence of a mutation having been found in a family, a negative test finding for a given individual is not informative. This does not mean that the cancer is not associated with a cancer susceptibility gene, only that no such mutation can be identified at this time.

The net result of all of these considerations is that not every individual is appropriate for testing. For the University of Pennsylvania Hereditary Breast and Ovarian Cancer Registry, the decision was made to analyze first already collected blood samples from affected women. If an affected woman was found to have a mutation, testing is offered to her family. As in other hereditary breast cancer registries, it has been found that many ostensibly high-risk families do not carry a known mutation of BRCA1 or BRCA2. This is stimulating a search for other genes associated with risk of breast cancer, but it also means that, for now, many women in the sample will not receive testing. Some have already been sent a letter explaining the predicament of their families with respect to testing. These women will continue to be studied. Essentially they had met criteria for inclusion in the registry, and based on this, they were led to believe that genetic testing would be an option. They are not being told that they are not members of a hereditary breast and ovarian cancer family, only that the families are not characterized by a known mutation of BRCA1 or BRCA2. This outcome is worthy of investigation and may have attendant psychological distress and other untoward consequences associated with it. Fortunately, we have baseline assessments of these women and as noted above, we have instituted interim and follow-up assessments of them.

Women in the Hereditary Breast and Ovarian Cancer Registry are scattered across the country. In order to receive results, women who are not located in close proximity to the University of Pennsylvania, University of Michigan, or other select sites must identify a physician and through that physician, provide a clinical consent. Only then will results be released. Concerted efforts are being made nationally to increase the availability of individuals qualified for counseling, disclosure of results, and follow up. The shortage of such physicians and some difficulties in their understanding of the consent process led to some delays early in the project, but physician shortage is no longer a barrier to the release of test results. In fact, recognizing that alternative methods of delivering test results may be needed as demand for testing increases, we are designing a study specifically addressing the relative feasibility and effectiveness of telephone disclosure of test results by practitioners.

Measures

Our selection of measures meets or exceeds what was proposed in our original grant application. Copies of our battery of instruments are included as an Appendix B. Table 1 lists the study's main measures for proband women and husbands.

Table 1
Selected Assessment Measures

<u>PROBAND MEASURES</u>		
Questionnaire	Interview	Interim Assessment
Demographics	Contextual Rating of	HSCL-25, MOS-36
Health Locus of Control	Cancer Threat:	Cancer Worries
Risk Perception	Affected Relatives	FAD, Short-Form DAS
Intention to Seek Testing	Relationship to	Quality of Social Support
Knowledge, Beliefs and Attitudes	Proband	Life Cycle Issues
Reasons for Seeking Testing	Outcome	Receipt of Individual,
Cancer Worries	Involvement of	Group, & Family, Counseling & Education
Stressful Life Events	Proband In Care	COPE
Optimism (LOT)	Effects on Proband's	Relationship-Focused Coping
Miller Behavioral Styles Scale (MBSS)	Life	CBCL
Hopkins-25, MOS-36, AUDIT	SCID Depression , Anxiety, & Substance Use Modules	Evaluation of Preventive Options
Dyadic Adjustment (DAS)	Cancer-Specific Support Processes	
General Family Functioning (FAD)		
Social Support & Cancer-Related Support Processes		
<u>HUSBAND QUESTIONNAIRES</u>		
Demographics	COPE	Stressful Life Events
Health Locus of Control Risk	Knowledge, Beliefs and	CBCL
Perception	Attitudes Anticipated Reactions	LOT, MBSS, Hopkins-25, MOS
Worries About Wife's	Social Support & Cancer-	36
Risk of Cancer	Related	AUDIT
Preference for Wife's Testing	Support Processes	DAS, FAD
Relationship-Focused Coping		

Sample

Our sample currently consists of 515 women who have completed baseline assessments. Of these, 492 completed the telephone interviews. To date, 401 interim assessments have been collected. Data from husbands are collected at the point of the women's interim assessment, and at this time, data have been collected from 246 husbands. Pre-Results data have been collected from 62 proband women. As of this report, 34 women have had their first post-results assessment, 33 have progressed to 6-month follow-up, and 16 have completed 12-month follow-up assessments. We expect the rate of delivery of test results to increase markedly over the next 4-6 months, and thus we anticipate a significant increase in follow-up data during the next year of the project. Table 2 presents an update of basic demographic data on the proband women. They are similar to other samples of persons seeking genetic services in that the majority are married, relatively well educated, and earning high incomes.

Table 2
Basic Demographic Data

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
Age	48.52 (12.07)	46.15 (12.06)	51.58 (11.40)
Religion:			
Christian	72.5%	78%	69.6%
Marital Status:			
Married/with partner	81.4%	81.9%	85%
Number of Children	2.09 (1.38)	1.95 (1.39)	2.25 (1.35)
Education:			
At least some college	78.8%	81.8%	79.4%
Employed Outside Home	61.4%	64.5%	60.7%
Annual Household Income	\$50,000	\$50,000	\$50,000

Psychological Distress

The 25-item version of the Hopkins Symptom Checklist (HSCL-25) was used to assess psychological distress. Heshbacher, Downing, and Stephansky (1978) found this version of the questionnaire reliable and highly correlated with the standard 58-item version (Derogatis et al., 1974). The HSCL-25 has a better balance of sensitivity and specificity than a number of other screening instruments such as the CES-D (Heshbacher et al. 1978; Hough et al. 1982). There is extensive data using this scale with healthy, physically ill, and psychiatric samples (Cohen, Coyne, & Duvall, 1993; Coyne & Smith, 1991; Coyne & Sonnega, 1995, Pepper, Coyne & Cohen, 1996).

Reports for previous years have detailed results related to psychiatric morbidity and the performance of screening instruments in making accurate psychiatric diagnoses. In these initial analyses, the Hopkins Symptom Checklist served as the measure of distress and a telephone interview using modules of the SCID served as the measure of current and lifetime psychiatric morbidity. These data were analyzed in conjunction with baseline data concerning intention to get test results and cancer worries. In the second year, we modified our earlier results based on continued accrual of subjects, although the pattern of remarkably low distress and psychiatric morbidity remained. Additionally, we completed sophisticated analyses of the performance of screening instruments. As dictated by the low prevalence of psychiatric disorder, the positive predictive value of screening for distress is quite low. These analyses suggest that screening for psychiatric morbidity is neither needed nor efficient.

Because the prevalence of psychiatric morbidity is extremely low in our sample, data presented here will be limited to variations in psychological distress that represent largely sub-clinical symptomatology. Also, while the Hopkins self-report measure is not a diagnostic tool, there are established cut-offs for identifying potentially clinically-significant distress. Table 3 (see next page) presents mean Hopkins scores and percentages of women meeting or exceeding the clinical cut-off for depressive symptomatology. These results have changed only slightly with the accrual of more women. Our sample, both affected and unaffected, is remarkably free of distress. Generally, women report relatively low levels of distress, with no differences in distress between unaffected and affected women.

The finding that about one-quarter of women meet or exceed the clinical cut-off requires further exploration. Recently published studies suggest that depressive symptoms in response to stressful events (such as cancer or genetic testing for cancer) can be explained in large part by accounting for past history of depressive episodes (Maunsell, Brisson, & Deschenes, 1992; McDaniel, Musselman, & Nemeroff, 1997; Schover, 1991). Our extensive baseline assessment allows for explicitly testing the contribution of depression history to current depressive symptoms during the potentially stressful process of genetic testing.

Table 3
Psychological Distress

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
Hopkins 25	37.6 (9.15)	37.4 (9.08)	37.82 (9.25)
% Above Clinical Cutoff of 43	22.3%	23.6%	22.0%

Interest in Obtaining Testing

Table 4 presents data concerning the intention to receive testing when it is offered. As can be seen, the majority of women express interest in obtaining results, with affected women significantly more likely to report intention to get testing immediately. It remains to be seen the extent to which this expression of interest is reflected in the women actually choosing to receive their results when the opportunity is presented to them. Once the next batch of test results are made available to a large group of women, we will evaluate the match between intention for testing and actual uptake of testing. Our extensive baseline and follow-up assessments will allow us to test the role of a full battery of psychosocial predictors in explaining any observed discrepancy.

Table 4
Intention To Receive Test Results

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
Definitely Will Immediately	53.9%	48.3%	63.6%***
Definitely, Not Sure Immediately	11.6%	15.8%	7.0%**
Probably Will Immediately	11.4%	13.1%	9.8%
Probably Will Not Immediately	7.9%	9.3%	6.5%
Undecided	7.2%	8.9%	5.6%
Probably Will Not	2.7%	2.3%	3.3%
Definitely Will Not	1.2%	1.2%	1.4%

***p < .001 **p < .01

Table 5 provides data concerning the women's reasons for obtaining test results. It appears that women with and without a personal history of cancer diagnosis seek genetic testing for different reasons than women with a personal history of cancer. Women without a personal history of cancer are significantly more likely than affected women to seek testing for most reasons, including those related to planning for the future, modifying screening behavior, and reducing uncertainty. While both affected and unaffected women reported seeking testing to clarify their children's cancer risk, women with a personal history of cancer were significantly more likely to be motivated by this factor. This result is consistent with our anticipation of the salience of such family issues in the reasons for undergoing testing. Moreover, now that it has been decided that testing is appropriate for unaffected women only when they are members of families with known mutations, the saliency of family issues for affected women is likely to increase.

Table 5
Reasons For Seeking Testing

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
To Plan for Future	38%	50.96%	24.8%***
To Reduce Uncertainty	53.5	66.4	40.7***
To Be More Careful About BSE	30.8	40.9	20.1***
To Decide About Prophylactic Surgery	37.4	47.5	27.1***
To Decide About Family Planning	6.4	9.3	3.3**
To Assess Risk To Children	54.3	45.2	68.2***
Family Urges Testing	11.4	11.2	12.1

*p < .05 **p < .01 ***p < .001

Perceived Risk of Breast Cancer

Table 6 summarizes women's perceived risk of breast cancer. Consistent with findings from other registry samples (Lerman, Kash, & Stefanek, 1994), women in this sample perceived their risk for breast cancer as fairly high. One interesting comparison is that of women's perceived risk of cancer and their objective risk based on established criteria. Because of our transfer to the University of Pennsylvania, and the closer collaboration with the medical team that this affords us, we were able to compare women's subjective risk estimates with estimates of their objective risk for breast cancer, based on criteria routinely used as part of the genetic counseling process at the Cancer Risk Evaluation Program clinical service. Specifically, the CREP service estimates women's objective risk of cancer using the Claus model (Claus et al, 1994), which predicts lifetime risk by accounting for cancer occurrence and age of onset in first-degree and second-degree relatives. Claus estimates are only estimated for unaffected women, because lifetime risk estimates among women with a personal history of cancer are not meaningful. On average, women tended to overestimate their perceived risk of cancer relative to objective Claus risk estimates, which averaged 22.55 (SD = 10.77), and ranged from 8.30 to 48.40.

Interestingly, women with a personal history of cancer perceived themselves as significantly less likely to get cancer than unaffected women, both in the near future and over their lifetimes. We will examine further the possibility that affected women perceive themselves as somehow protected from future cancer occurrences, as this finding has profound implications for clinical intervention with affected women.

Table 6
Perceived Likelihood Of Breast Cancer

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
In the Near Future	36.4%	44.2%***	26.5%***
In Lifetime	50.9%	62.7%***	36.2%***

***p < .001

Breast Cancer Worries

A measure of cancer worries was administered only to women without a personal history of cancer. The women were asked how often they worry about developing breast cancer and also the extent to which their worries interfered with their everyday lives. These items had been validated in studies conducted by Caryn Lerman and her colleagues e.g. Lerman et al. 1994; Lerman & Croyle, in press; Struewing et al., in press). Table 7 presents the data derived from standard measures of breast cancer worries. Understandably, the women have a moderate degree of such worries. Of great clinical significance is the finding that, despite a moderate degree of worry, women report that such worries do not substantially interfere with their lives.

Table 7

Breast Cancer Worries Among Unaffected High Risk Women

How often do you worry about developing breast cancer (1= Not at All, 5= All the Time)?	2.88 (.98)
To what extent do any worries about breast cancer interfere with your life (1= Not at All, 5= All the Time)?	1.65 (.93)

Other studies have employed similar measures of breast cancer worry among high-risk and other women, and have reported similarly low to moderate levels of cancer worry, and even lower degrees of interference with functioning. For instance, posing similar questions to women with and without a family history of cancer, McCaul et al (1998) report average breast cancer worry among women with a family history of cancer as 2.65 (SD = .69, with a possible range of 1 to 5). Further, these women rated the degree to which these worries interfere with their performance of daily activities as 1.17 (SD = .38, with a possible range of 1 to 5). Lerman, Kash, & Stefanek (1994) assessed cancer worry and interference among younger women with a family history of cancer, and report average worry as 2.53 (SD = 1.66, with a possible range of 1 to 7), and the impact of these worries on daily functioning as 1.54 (SD = .84, with a possible range of 1 to 4). Although the Lerman et al study uses slightly different scales, it is notable that women in this study, as well as the McCaul et al study, report similiary low levels of worry and interference.

Husband Functioning

Table 8 summarizes husband's reports of functioning at baseline assessment and at approximately 8 months after their wife-probands received genetic test results. Because of small sample sizes for follow-up, comparisons between time points should be considered tentative, but we anticipate a significant increase in husband follow-up assessments as the number of women seeking testing increases with the release of a large number of test results. Recognizing their limitations, this initial data seems to suggest that husbands report fairly low and stable levels of psychological distress and worry related to their wives developing breast cancer. Husbands' perceptions of their wives' lifetime risk of breast cancer appear to decrease after testing, although it remains to be seen whether this decrease is statistically significant, or perhaps more importantly, whether it is clinically significant.

Table 8
Husband Functioning at Baseline and Follow-up Assessments

	Baseline (n=226)	8-Month Follow-Up (n=13)
Psychological Distress (Hopkins)	34.74 (7.94)	37.38 (8.24)
Worry about Wife Developing Breast Cancer (1= Not at all, 5= All the time)	2.85 (1.17)	2.23 (1.01)
Interference from Breast Cancer Worries (1= Not at all, 5= All the time)	1.78 (.91)	1.38 (.77)
Perceived Short-Term Risk of Wife Developing Breast Cancer	24.84% (24.00)	26.92% (19.32)
Perceived Lifetime Risk of Wife Developing Breast Cancer	36.62% (28.65)	29.23% (20.60)

Interim Functioning

In anticipation of longer delays between baseline assessment and actual receipt of test results, we added an interim assessment to our already comprehensive schedule of follow-ups. The interim assessment was given to women for whom test results were not available one year after baseline assessment. The main purpose of the interim assessment was to continue to monitor women's experiences with the genetic testing process, and to ensure that we had up-to-date measures of areas of functioning that might change over time (i.e., states rather than traits). This interim assessment gives us the additional benefit of being able to test hypotheses regarding causal relationships between variables, instead of relying on inferences from concurrently-collected data.

Like the investigator team, many women who joined the cancer registry, and specifically this study of the genetic testing process, did not anticipate that the process would take so long. One important question addressed by the interim data is the psychological impact this delay in testing has had on women and their families. A variety of different scenarios are possible, including that genetic testing does not add to the stress of a family already touched by cancer, that genetic testing may be stressful but that women habituate to the stressors involved, or that a long delay between the possibility of testing and availability of results locks women and their families in a long-term stressful experience.

Table 9 (see next page) compares key indicators of functioning of affected and unaffected proband women at baseline and interim assessment points. Of particular interest are the findings that the delay in testing does not appear related to increased psychological distress, either among unaffected or affected women. Also, intention for testing appears to increase over the waiting period, suggesting that women did not appear to get discouraged from testing because of unexpected delays in the availability of results. Finally, women's reports of optimism increased significantly from baseline to interim assessment. Given our thorough assessment of personality, functioning, and social variables, and the longitudinal nature of our data, we will be able to explore alternative explanations for this interesting finding.

Table 9
Functioning at Baseline and Interim Assessments by Breast Cancer Status

	<u>UNAFFECTED WOMEN</u>		<u>AFFECTED WOMEN</u>	
	Baseline	Interim	Baseline	Interim
Psychological Distress (Hopkins)	37.35 (9.08)	36.86 (8.92)	37.82 (9.25)	37.47 (9.52)
Breast Cancer Worry (1= Not at all, 5= All the time)	2.88 (.98)	2.73 (.98)	2.50 (1.05)	2.72 (1.02)
Interference from Worry (1= Not at all, 5= All the time)	1.65 (.93)	1.48 (.77)	1.67 (.82)	1.48 (.77)
Intention for Testing (1= Definitely seek testing immediately when available, 7= Definitely not seek testing)	2.25 (1.55)	2.45 (1.55)	1.96 (1.57)	2.63 (1.61)
Life Events (Number of life events)	1.0 (1.24)	.79 (1.10)	1.03 (1.19)	.87 (1.09)
Optimism (Life Orientation Test)	29.63 (5.58)	43.13 (9.41)	29.97 (6.14)	42.55 (10.05)

Impact of Genetic Testing

As more women are being offered test results, we are beginning to accrue more follow-up data describing women's experiences with genetic testing. Because of small sample sizes, comparative analyses are not yet appropriate, but the following tables present preliminary descriptive data on the impact of testing on different areas of women's lives (Table 10, see next page), and women's responses to testing (Table 11, see next page). Worth noting in Table 10 is the relative lack of impact of genetic testing on women's family or work functioning, or on women's life overall, but the seemingly negative impact of genetic testing on women's anxiety

about the future and health care decisions. Of significance in Table 11 are the low to moderate levels of distress reported after testing, and women's lack of regret for testing, even among women for whom a genetic mutation was detected. However the large standard deviations suggest great variability in this small sample, and emphasize the need to be cautious in drawing conclusions before collecting more follow-up data. Also, the women receiving uninformative results seem to be an interesting group for further study, with apparently slightly higher regret about testing than women receiving other results.

Table 10
Impact of Genetic Testing at 6-Month Follow-up (Interview)

	All Women (n = 35)	Uninformative Results (n = 21)	Negative for known mutation (n = 1)	Positive for known mutation (n = 5)
Effect of testing on your family (1= Very negative effect, 3= No effect, 5= Very positive effect)	3.46 (.70)	3.35 (.65)	4.00 (.00)	3.40 (.89)
Effect of testing on your work (1= Very negative effect, 3= No effect, 5= Very positive effect)	3.06 (.42)	3.00 (.30)	3.00 (.00)	3.40 (.89)
Effect of testing on your concerns for child's future (1= Very negative effect, 3= No effect, 5= Very positive effect)	3.44 (1.08)	3.19 (.98)	2.00 (.00)	3.80 (1.30)
Overall effect of testing on your life (1= Very negative effect, 3= No effect, 5= Very positive effect)	3.54 (.70)	3.39 (.58)	4.00 (.00)	3.80 (1.10)
Effect of testing on your anxiety about the future (1= Very negative effect, 3= No effect, 5= Very positive effect)	1.77 (.60)	1.83 (.58)	1.50 (.00)	1.80 (.84)
Effect of testing on your health care decisions (1= Very negative effect, 3= No effect, 5= Very positive effect)	1.40 (.77)	1.61 (.89)	1.00 (.00)	1.00 (.00)

Table 11
Responses to Genetic Testing at 6-Month and 12-Month Follow-ups (Questionnaire)

6-Month Follow-Up				
	All Women (n = 20)	Uninformative Results (n = 15)	Negative for known mutation (n = 2)	Positive for known mutation (n = 3)
Distress Upon Receiving Results (1= Not at all, 5= Very distressed)	2.3 (1.45)	2.3 (1.45)	1.5 (.71)	2.67 (2.08)
Regret Decision to Be Tested (1= Not at all, 5 = Very much so)	1.35 (.93)	1.47 (1.06)	1.00 (.00)	1.00 (.00)
12-Month Follow-Up				
	All Women (n = 15)	Uninformative Results (n = 10)	Negative for known mutation (n = 2)	Positive for known mutation (n = 3)
Distress Upon Receiving Results (1= Not at all, 5= Very distressed)	1.73 (1.39)	1.70 (1.25)	1.00 (.00)	2.33 (2.31)
Regret Decision to Be Tested (1= Not at all, 5 = Very much so)	1.27 (.80)	1.10 (.32)	1.00 (.00)	2.00 (1.73)

Changes in Functioning Over Time

Several measures of functioning are assessed at multiple time points during the study, allowing for modeling of change in functioning over time. Two key indicators of functioning are psychological distress and breast cancer worries. Small sample sizes for follow-up preclude comparative analyses at this time, but the following figures illustrate patterns that may persist with the inclusion of new follow-up data. Figure 1 and 2 illustrate women's reports of psychological distress and breast cancer worries at baseline assessment, interim, and 2 months, 6 months, and 12 months after receipt of results.

Figure 1

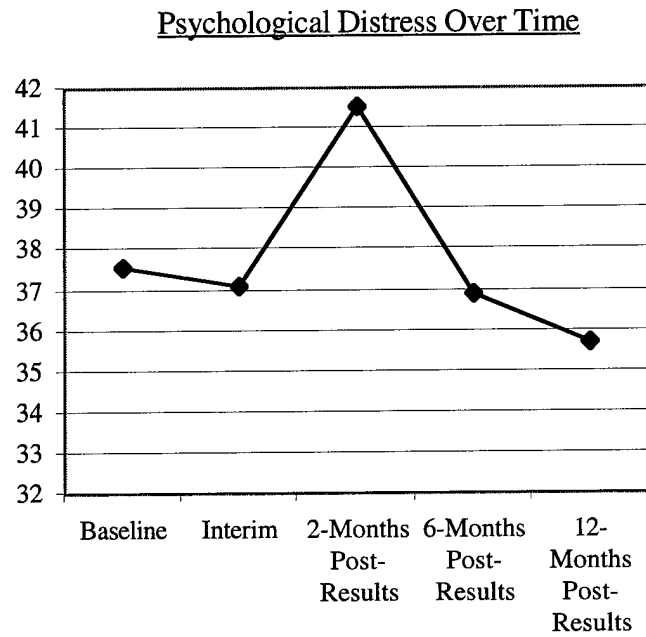
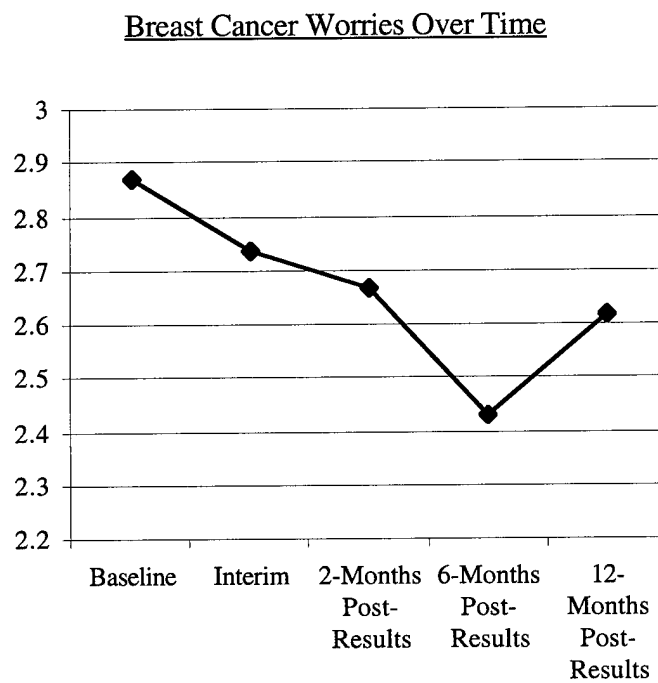


Figure 2



Women appear to experience an increase in psychological distress during the few months immediately after receiving their genetic test results. Optimistically, even at their most distressed, women do not exceed the criteria for clinical symptomatology, and this distress seems to resolve to below-baseline levels by 12-month follow-up. Further, women's experience of breast cancer worries seems to decline through the process of genetic testing, with a small increase at 12-month follow-up. Although preliminary, these longitudinal data suggest that women manage the process of genetic testing effectively, with some variations in distress and worry that fall well within the normal range.

CONCLUSIONS

While analyses are ongoing, both in terms of describing baseline functioning and in predicting follow-up functioning, some initial conclusions can be drawn from analyses completed to date. One important conclusion is that, at least among this group of self-selected women, reports of extreme psychological distress and, especially, psychiatric diagnoses, were rare. At their baseline assessment prior to being offered genetic testing, both women affected and as-of-yet unaffected by breast cancer were remarkably free of psychological distress and psychiatric morbidity. Despite their increased risk for breast and ovarian cancers, as well as their repeated exposure to breast cancer personally or through their relatives, they appeared resilient in the face of the potentially stressful experience of genetic testing. Our findings have a number of implications. Most importantly, it appears that when women approach the process of counseling, education, and decision making about testing, they will not be impaired by their pre-existing psychological state. That is not to say that the actual experience of counseling, having to make a decision about testing, or the receipt of positive results will not engender distress. However, the assumption that these women will approach the process of genetic testing with distress and psychiatric morbidity was not substantiated by our findings. Rather, the results suggest that any substantial elevations of distress and psychiatric morbidity following the counseling process are best attributed to that process and not to the preexisting state of the women. It follows that efforts to manage psychological distress and the education and consent process should focus on acute needs, rather than be based on the assumption of chronic psychological problems.

Further, preliminary analyses of responses of women who have completed assessments through 12-month follow-ups suggest this pattern of resiliency and little distress persists over time. Looking at changes in psychological distress through the course of the genetic testing process, it appears that there may be a slight increase in reported distress during the few months after receiving test results, but that this increase does not reach clinical levels of symptomatology, and resolves to levels below those reported by women at baseline assessment.

These distress findings have a number of implications that go beyond the question of determining the psychological state of women seeking predictive testing for risk of breast cancer. We have demonstrated that long-term survivors of cancer can be relatively free of psychological distress and psychiatric morbidity. Even though over half our sample were survivors of breast cancer, and had a greater lifetime incidence of depression than the unaffected women, these women were well within the expected prevalence for a representative sample of community-residing women. The low levels of distress and morbidity reported in this study suggest that previous findings of elevated distress may be confined to early adjustment to a diagnosis of cancer, or to the

advanced stages of the disease. Our findings add to accumulating evidence that cancer does not necessarily result in psychiatric morbidity. We believe that attention can be more productively directed at better understanding why these women defy the not unreasonable assumption that they are a distressed, depressed, and anxious group. The experience of living with familial risk of cancer may well have had a resiliency-building effect that more than cancels any vulnerability associated with it. The particular aspects of this experience, that cultivates resiliency and vulnerability, need to be specified. As others have noted, adversity can produce resiliency as well as vulnerability, and women anticipating testing provide an excellent opportunity to study this (e.g., Schaeffer & Moos, 1992).

An alternative explanation for the relative lack of distress reported by women in this sample is that the cancer registry draws a highly selective group of women. We certainly found that our sample is unusually stable - psychologically, financially, and maritally. We remain concerned about the generalizability of our findings, and those of other investigations of high-risk women drawn from registry samples. Members of high-risk families jointly participate in these registries, and they typically have marshaled considerable social support to manage their shared sense of being at high risk for cancer. Participation in these registries has also given these women exceptional opportunities to become informed about their risk of cancer and genetic testing, to come to terms with their risk status, and to evaluate the advantages and disadvantages of testing for themselves and their families.

In contrast, women from the community seeking testing are likely to be less socially advantaged, and less informed about, or are psychologically ill-prepared for, the dilemma of whether to proceed with testing. For these women, the decision to pursue testing may be precipitous and tied to recent stressors, such as positive mammography findings, or the diagnosis or death of a family member. Pre-existing psychological distress may impair these women's efforts to become educated about, and to decide on, the merits of testing for them. They may be naive about the potentially negative insurance issues and social discrimination associated with being known to have an altered gene. Social support related to being at high risk and to deciding about testing may be deficient or absent. Without appropriate services these women may obtain testing without giving adequate informed consent, which may have negative psychosocial consequences rather than the intended benefits of testing. Yet, at the present time, we lack the knowledge needed to specify just what services are appropriate. To address this lack of knowledge, we are developing projects to compare our registry sample with women from a largely African-American community, and with women seeking clinical services through the Cancer Risk Evaluation Program at the University of Pennsylvania Cancer Center. The intent of this work is to identify selection biases and discrepancies in experiences of registry and community women, data

that will have direct and immediate application in the refining and evaluating of urgently needed clinical protocols.

In addition to clarifying distress and characteristics unique to our sample, we also uncovered interesting differences between women with a personal history of cancer, and those without, in terms of perceived risk of breast cancer, and motivation and intention to seek testing. For instance, women with a personal history of breast cancer perceived their short-term and lifetime risks of breast cancer as significantly lower than women without a personal history. Further analyses will explore possible explanations for this finding, including the degree to which it can be explained by a sense that one cancer event may protect against future events, that affected women perhaps feel more confident in their screening plan, or that past treatments, such as mastectomy, confer a lower sense of risk. Also, affected women were significantly more likely than other women to report they intend to seek testing immediately after it becomes available, and to pursue testing in order to clarify their children's risk of cancer. Also, all women overestimated their lifetime risk of breast cancer relative to objective risk estimates, suggesting that perhaps psychosocial factors such as salient experiences with family members affected by cancer, or frequent focus on cancer and health may influence risk perception beyond objective information. Our data allow us to investigate these hypotheses.

Due to the progression of some women through 12-month follow-up assessments during the third year, we are beginning basic descriptive analyses of longitudinal data. Preliminary analyses with the few women who have progressed through follow-up suggest that women are generally satisfied with their decision to obtain test results, and that receiving results does not have a significant negative impact on women's lives, in terms of increasing psychological distress, worry, or interfering with work or family functioning. Also, although tentative given the current small sample sizes for follow-up, it appears that of the three types of results women can receive—positive for a known mutation, negative for a known mutation, and uninformative—there may be a psychological cost to participating in genetic testing resulting in uninformative results. As more follow-up data become available, it will be possible to look more critically at the potential negative impact of increased focus on risk without conclusive genetic results.

In conclusion, our project continues to make substantial progress in data collection, analysis, and publication, and in establishing opportunities for collaboration and expansion of the current study. Such collaborations maximize the utility of the data already collected, and help us more easily to overcome a variety of methodological and logistical challenges. The excellent mental health of these women shifted the focus of our research from efforts to predict baseline vulnerability to an attempt to understand their resiliency in the face of their risk for breast cancer. As a byproduct of this effort, we produced data, from our affected women, that are optimistic concerning the mental health of longer-term cancer survivors.

In our third year we continued with data collection, responding to changes in geography and technology related to the project, and began to publish data from the project. In manuscripts currently in press, we described the psychological functioning of women in the registry sample, both at baseline assessment and at time points along the process of genetic testing, and are able to state, with some authority, that women in this registry sample managed well the process of genetic testing. We also described the social support processes among high-risk women in the cancer registry. We have begun to explore explanations for observed differences between affected and unaffected women, regarding risk perception and intention and motivation for testing. We have also begun to describe the experiences of husbands and sisters of high-risk women, and will continue with data collection and analyses through the fourth year of the project.

Additionally in our fourth year, we intend to gather substantial follow-up data in response to the anticipated large uptake of genetic testing results as they are completed by the lab and released to registry women. We intend to implement the collaborative studies discussed earlier, and to continue to develop opportunities for further collaboration to maximize the utility of data from the present study. Substantively, we plan to address the issues of selection bias in the registry sample, and assess the experiences of women with different socioeconomic backgrounds and different motivations for contacting the health system. We also plan to conduct analyses clarifying relationships between different aspects of women's experiences, taking full advantage of the longitudinal nature of this study and the unique opportunities this affords for causal modeling.

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APPENDIX A
Copies of Manuscripts in Press

RUNNING HEAD: Marriage and Support

Marital Status, Marital Satisfaction, and Support Processes
Among Women at High Risk for Breast Cancer

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Abstract

This study explored marital status, social support processes, and psychological distress among women at high risk for breast and ovarian cancer who were anticipating genetic testing. In addition to substantive findings, it presents a means of using nonsense coding (Cohen & Cohen, 1983) to include unmarried persons in regression analyses examining the importance of marital support. These women had mobilized high levels of social support. Married and unmarried women did not differ in distress, but women had to have more satisfying marriages than average to be equivalent to unmarried women. For the married, husbands were more involved, and more influential in decision-making than female relatives, even in distressed marriages. Negativity from close relationships, particularly the spouse, had more influence on these women's well-being than did positive involvement. Our findings suggest that counseling and education programs need to accommodate the key role that husbands have in decision-making.

Marital Status, Marital Satisfaction, and Support Processes
Among Women at High Risk for Breast Cancer

Social support from the husband and close family members has been identified as a key resource in the adjustment of women to the diagnosis and treatment of breast cancer (Bloom, 1996; Lichtman, Taylor, & Wood, 1987; Manne, 1998; Peters-Golden, 1982; Pistrang & Barker, 1995). By extension, such social support should be an important determinant of women's ability to adjust to an awareness that they are at high risk for cancer. Women's knowledge that they are members of a high-risk family involves a recognition that they are personally at a heightened risk for cancer, that they may need to make decisions as to how to manage this risk under conditions of considerable ambiguity, and that they may have transmitted this risk to their children.

The present study explored marital status and social support processes in relation to psychological distress among women who were considered at high risk for breast and ovarian cancer on the basis of personal and family history. Some of these women were deemed at high risk because they already had a diagnosis of breast cancer or ovarian cancer, and had at least one other family member who had been diagnosed with one of these cancers. These women have a greater likelihood of contralateral breast cancer and ovarian cancer than do women without a family history. Other women in this study had not been diagnosed with breast or ovarian cancer themselves, but had at least two relatives who had been diagnosed with one of these forms of cancer. All of the women in this study had previously been enrolled in the registry of the Hereditary Breast and Ovarian Cancer Study conducted by the University of Michigan and, later, the University of Pennsylvania Cancer Center. They were assessed for social support and psychological distress at an important time: while they were anticipating the offering of genetic testing to them which could reveal whether they had an altered gene associated with an increased risk of cancer. The Hereditary Breast and Ovarian Cancer Study was originally conceived primarily as basic research, not as a clinical project. However, it became possible by the early 1990s to

perform linkage analyses so that for a few families it could be determined whether a particular member of the family had an increased risk of cancer. Experience disclosing the results of linkage analyses to some of these families highlighted the complex psychosocial issues involved in making such information available (Biesicker et al., 1993). Moreover, it was apparent, at the time, that a gene associated with increased risk of cancer would soon be isolated, and more widespread testing would then become possible. A research project was initiated examining psychosocial issues associated with genetic testing in the Hereditary Breast and Ovarian Cancer Study sample of women, and the data reported in this paper are derived from baseline assessments. These data were collected in late 1995 and early 1996, starting the year after the announcement that a strong candidate for the breast and ovarian cancer susceptibility gene BRCA1 had been identified (Miki et al., 1994), and a time when the offering of genetic testing was widely expected to be imminent. Furthermore, there was the anticipation that BRCA1 would account for more familial breast cancer than actually proved to be the case, and that genetic testing would provide more information to these women than it has (Couch et al., 1997).

There had been concerns that positive findings would carry the threat of psychological and psychiatric morbidity for the women and their family members, disruption of family relationships, and the impairment of the women's surveillance and adherence behaviors. There were also concerns that, among the high-risk women seeking testing, an existing level of distress or vulnerability to major depression might impair their ability to become educated, make an informed choice about testing, and utilize their test results to manage their risk of cancer. However, initial findings indicate that the high-risk women anticipating genetic testing are remarkably free of psychological distress and clinical depression and anxiety disorders (Coyne, Benazon, Calzone, Weber, & Gaba, 1998). They have less distress and psychiatric morbidity than do women drawn from the waiting rooms of primary care physicians (Coyne, Fechner-Bates, & Schwenk, 1994; Fechner-Bates, Coyne, & Schwenk, 1994). Moreover, receipt of results revealing that women have

an altered gene associated with heightened risk of cancer produced only mild and temporary elevations in distress (Lerman et al., 1996). Given findings concerning the relative lack of distress and depression among these women, what was designed as a study of their vulnerability needs to be reconceptualized as a study of their robustness and resiliency.

Questions remain about the representativeness of women drawn from hereditary breast cancer registries, and, therefore, the generalizability of results of studies of the psychological effects of genetic testing conducted with them. These registry women are self-selected and socially advantaged in terms of education and income (Coyne et al., 1998). Members of high-risk families jointly participate in these registries, and, in the process of accumulating family history data, they typically have marshaled considerable social support to manage their shared sense of being at high risk for cancer. In contrast, women from the community seeking testing are likely to be less socially advantaged. They are also likely to be less involved in discussions with family members about their risk of cancer, less informed about genetic testing, and less psychologically unprepared for the dilemma of whether personally to proceed with testing. Social support related to being at high risk and to the decision about testing may be deficient or absent. Important in itself, an understanding of support processes among the high-risk registry women may also prove useful in defining how they differ from women in the community seeking testing, and in the design of compensatory services for the women from the community.

Because a considerable proportion of the women in our sample had already been diagnosed with breast cancer, we were able to compare them to women who were high-risk, but without a personal history of cancer. Most of the women were currently married, but there were sufficient numbers of unmarried women to examine some differences in support processes between married and unmarried high-risk women. There has been a long-standing interest in the role of marriage in the well-being of women, but the bulk of research has focused on comparisons between married women and men, rather than on differences between married and unmarried women (Kessler & McRae, 1984). However,

married women have been found to be less distressed than unmarried women in some community studies (Kessler & McRae, 1984; Williams, 1988. See Wood, Rhodes, & Whelan, 1989, for a review), as well as rating themselves happier (Stack & Eshleman, 1998). Furthermore, spouses are generally the most important sources of support for married persons (Brown & Harris, 1978; Coyne & DeLongis, 1986). There is some limited evidence that women in strained marriages may actually be worse off than unmarried women (Aneshensel, 1986; Cutrona, 1996; Weissman, 1987), and that support from other sources will not compensate for what is lacking in the marriage (Brown & Harris, 1978; Coyne & DeLongis, 1986). Yet, the women in our study are members of high-risk families, with first-degree female relatives in similar predicaments. The support and information close female relatives provide, how these relatives cope with their own dilemma, and the decisions about testing they make are likely to have profound effects on the high-risk women. It may be that, as a result of the mobilization of social support around the shared risk of cancer, female relatives have more, and spouses correspondingly less, influence on the level of psychological distress of these women.

Finally, involvement in close relationships can be a liability, as well as an asset, in coping with chronic illness (Cutrona, 1996; Fiske, Coyne, & Smith, 1991; Lyons, Sullivan, Ritvo, & Coyne, 1995). Husbands of cancer patients are often fallible as sources of support, even if they are important determinants of the women's well-being. Women may find exchanges with their husbands less helpful than with female relatives who are similarly at risk for cancer, and husbands' avoidance of open discussion about risk could be problematic (Pistrang, Barker, & Rutter, 1997). So, it becomes important to examine negative as well as positive aspects of involvement in social relationships. Here, too, the mobilization of support among female relatives may decrease the importance of the marital relationship.

An understanding of the psychosocial resources of high-risk registry women anticipating genetic testing has practical implications. Moreover, the opportunity to study this large sample of women at this key point in time also allowed us to explore some more general theoretical issues. These include social support processes among married and unmarried women; the robustness of findings concerning marriage as the key source of support for married women; and the relations between perceived support to specific support processes to compare the importance of husbands' and female family members' opinions in the women's decision-making processes about genetic testing and risk-reduction behaviors.

Method

Sample and Recruitment Procedure

Women participating in the study were drawn from the registry of the Hereditary Breast and Ovarian Cancer Study conducted first by the University of Michigan and subsequently at the University of Pennsylvania Cancer Center. To be included in the registry, women who had no personal history of breast or ovarian cancer had to have at least two cases of either cancer in their family, and women with a personal history of breast or ovarian cancer had to have at least one other family member who had such a history.

In August of 1995, women who had previously been enrolled in the registry were sent a newsletter informing them of a study aimed at examining the psychological factors associated with anticipating and receiving genetic testing for risk of breast and ovarian cancer. The newsletter gave them the opportunity to decline further solicitation concerning this study. Questionnaire packages and consent forms were then mailed to the homes of the women who did not decline further solicitation. A cover letter was included explaining to participants that, upon receipt of their questionnaires, a researcher would contact them to arrange a telephone interview. The letter emphasized that the information provided would be kept confidential. When participants were contacted by telephone, they were again provided with an explanation of the voluntary nature of participation. A follow-up letter

was sent and a query was made by telephone if women did not respond to the mailing by returning the questionnaire or declining participation in the study. An appointment was arranged for a telephone interview if women elected to pursue the next phase of the study when contacted by telephone after returning their questionnaire. On average, the questionnaires required 30 minutes to complete and the telephone interviews lasted approximately 45 minutes. All interviewers were trained and had graduate training in clinical psychology, social work, or nursing.

Of the 633 eligible women who were sent questionnaires, 477 (75%) returned them. Of the 156 women who did not return questionnaires, 54 declined participation and 102 did not return a questionnaire despite efforts to reach them by follow-up letter and telephone call. Our sense is that, for the most part, this latter group had simply been lost to the registry, rather than representing passive refusals. Of the 477 women who returned a questionnaire, 464 received a telephone interview. The final sample consisted of 211 women with a history of breast or ovarian cancer, and 253 without such a history. Of these 464 women, 394 were married ($n=380$) or living with a partner ($n=14$). For the purpose of the analyses presented in this paper, the unmarried women living with a partner were included in the married group, leaving 56 women in the unmarried group.

Key Measures

Cancer Status and Time Since Diagnosis. Registry records of the women's personal history of cancer were verified by self-report on the questionnaire. For women with a history of cancer, another item on the questionnaire inquired about the date of first diagnosis of breast or ovarian cancer. The difference between that date and the date on which the questionnaire was completed served as the length of time since diagnosis for the women with a history of cancer.

Perceived Social Support from Spouses and Female Relatives. Items derived from the Inventory of Socially Supportive Behaviors (ISSB; Barrera, Sandler & Ramsay, 1981) was used to assess women's perceptions of supportive and unsupportive behaviors from

their spouse and the high-risk female relative to whom they were closest. Women responded to 12 items using a yes-no format to indicate the extent to which both their spouse and female family member exhibited supportive behaviors (e.g., "listened to you talk about your private feelings"). They similarly responded to 3 items regarding unsupportive behaviors demonstrated by their spouse and female relative (e.g., "let you down when you were counting on him/her"). Coefficient alphas were as follows: supportive behavior from the spouse and closest at-risk female family member, .77 and .81 respectively; unsupportive behavior from the spouse and closest female relative, .69 and .77 respectively.

Cancer-Specific Social Support Processes. As part of the telephone interview, women were asked several questions scored on four-point Likert scales (1= not at all, 2= a little, 3= somewhat, 4 = a great deal) to assess their perceptions of how supportive their spouse and a sister have been surrounding their cancer or being at high risk for cancer. Note that, whereas the perceived support questions described above focused on the closest female relative, these questions inquired about a sister. By referring specifically to a sister, the intent was to focus on a female relative who was at equivalent risk to be a carrier of a gene mutation, but not on a relative, such as mother or daughter, for whom there might be issues of guilt and responsibility over transmission of the gene. These items addressed the frequency of discussions about cancer and genetic risk, women's satisfaction with these discussions, and the importance of the opinions of their spouse and sister in the decisions the women make about reducing their cancer risk and about getting genetic testing.

Psychological Distress. The 25-item version of the Hopkins Symptom Checklist (HSCL-25; Hough, Landsverk, Stone, & Jacobson, 1982) was used to assess psychological distress. It consists of the anxiety and depression items, and two somatic items from the standard 58-item version (Derogatis, Lipman, Rickels, Uhlenuth, & Covi, 1974), and the same items also appear with inconsequential differences in wording on the Symptom Checklist 90 (SCL-90; Derogatis & Cleary, 1977). Hesbacher, Rickels,

Downing, and Stepansky (1978) found that the HSCL-25 correlated highly with the standard 58-item version Hopkins Symptom Checklist (Derogatis et al., 1974). Using a cutoff of 43 for caseness, Hough et al. (1982) found that the HSCL-25 was comparable, or superior, to the CES-D (Radloff, 1977) in detecting psychiatric disorder, depending on the criterion employed. There are extensive data using this scale with healthy, physically ill, and psychiatric samples where adequate rates of reliability have been reported (Cohen, Coyne, & Duvall, 1993; Coyne & Smith, 1991; Cranford, Coyne, Sonnega, Nicklas, 1998; Hesbacher, Rickels, Morris, Newman, & Rosenfeld, 1980; Pepper, Coyne, & Cohen, 1996). Consistent with past studies, coefficient alpha for the HSCL-25 was found to be .91, indicating that general psychological distress is being assessed (Cyr, McKenna-Foley, & Peacock, 1985; Tennen, Affleck, & Herzberger, 1985).

Marital Adjustment. Marital adjustment was assessed using the Dyadic Adjustment Scale (DAS; Spanier, 1976). It is probably the most validated of such measures, having been used in well over 1,000 studies (Spanier, 1988). Factor analyses finding a single factor indicative of general marital satisfaction (Kazak, Jarmas, & Snitzer, 1988; Sharpley & Cross, 1982) suggest the use of a summary score rather than the four subscales that were originally proposed (Spanier, 1976).

Results

Demographic Characteristics. As a group, the women were white (98.1%), primarily Christian (74.2%), of middle age ($M=48.52$ years, $SD=12.07$ years), well educated (61.0% had at least completed college), and well-off financially (65.5% had a household income of at least \$40,000). Most were married (84.9%) and they tended to have stable marriages, as judged by the fact that 81% had been married only once.

Table 1 presents demographic variables for the women, classified down by history of cancer, and whether they were married or unmarried. In terms of differences, women with a history of cancer were significantly older than those without such a history, $F(1,440) = 25.47$, $p < .001$, and women who were not married were significantly older than those

who were, $F(1,440) = 24.76, p < .001$. Also, significantly more of the women with a history of cancer were Christian, $\chi^2(1) = 4.95, p < .05$. As might be expected, women who were married reported a higher household income than those who were not, $F(1,435) = 87.16, p < .001$.

Insert Table 1 here

Bivariate Pearson Correlations of Distress and Support Variables. Table 2 displays correlational analyses for the married women. As can be seen, the correlations were very similar for women with and without a history of cancer. Women's distress ratings were related to a lack of support from both their spouse and closest female family member at high risk for cancer. As can be seen, it is notable that there were also significant correlations between perceived support from female family members and support from spouses, and between unsupportive behaviors from relatives and unsupportive behaviors from spouses.

When the relevant correlations were examined for unmarried women, only one was significant. For women without a history of cancer, perceiving their female family members as supportive was negatively correlated with perceiving their female family members as unsupportive ($r = -.38$).

Insert Table 2 here

Differences in Psychological Distress and Perceived Support as Related to Cancer Status, Marital Status, and Marital Satisfaction. Three 2 (cancer history: yes, no) x 3 (marital status/satisfaction: not married, married dissatisfied, married satisfied) Analyses of Variance (ANOVAs) were conducted to examine differences in distress and social support from female family members. The cutpoint of 107 on the DAS was used to classify women

as being in a maritally-dissatisfied relationship (Crane, Allgood, Larson, & Griffin, 1990). Two-thirds (67%) of the women scored above the 107 cutpoint, thus indicating that they were in a satisfying marital relationship, with no differences between the groups with respect to history of cancer. For psychological distress, there was a main effect for marital status/satisfaction, $F(2,440)=20.06$, $p<.001$, but no significant main effect for history of cancer, $F(1,440)=.18$, $p=.67$, or interaction, $F(2,440)=.67$, $p=.51$. A Tukey Honestly Significant Differences post-hoc test revealed that maritally-dissatisfied women reported significantly more psychological distress than both unmarried women and satisfactorily married women. However, as can be seen in Table 3, the mean distress score for maritally-dissatisfied women was still below the clinical cutpoint on the HSCL-25 of 43. For support from female family members, there was only a significant effect for marital status/satisfaction, $F(2,395)=3.06$, $p<.05$, but no main effect for history of cancer, $F(1,395)=2.72$, $p=.10$, or interaction effect, $F(2,395)=.67$, $p=.51$. Again, a Tukey Honestly Significant Differences post-hoc test revealed that married women who were satisfied with their marriages reported significantly more support from female family members than did unmarried women. The amount of support from female relatives reported by maritally-dissatisfied women did not differ from that reported by both unmarried women and women in a satisfying relationship (See Table 3). In terms of unsupportive behaviors from female family members, there was no main effect for marital status/satisfaction, $F(2,389)=1.39$, $p=.25$, but women without a history of cancer reported receiving significantly more unsupportive behavior, $F(1,389) = 4.62$, $p < .05$. The interaction was not significant, $F(2,389)=.33$, $p=.72$.

In order to examine support that married women perceived from spouses, two similar 2(history of cancer) x 2(married dissatisfied, married satisfied) ANOVAs were conducted. Referring to Table 3, women who were not in a distressed relationship perceived significantly more support from their husbands than those in a distressed relationship, $F(1,353)=91.01$, $p<.001$. In addition, women without a history of cancer reported more

spousal support than those with a history, $F(1,353)=13.64$, $p<.001$. The interaction effect was not significant, $F(1,353)=.60$, $p<.40$. As would be expected, women in a distressed relationship perceived more unsupportive behaviors from their spouses than did women who were not in a dissatisfied relationship, $F(1,342)=70.92$, $p<.001$. There was not a significant main effect for history of cancer, $F(1,342)=1.05$, $p=.31$, or an interaction effect, $F(1,342)=.58$, $p=.45$.

An interesting question which is seldom answered in the empirical literature concerns the level of marital satisfaction required to render married women equivalent to unmarried women in psychological distress. This question can readily be addressed in the following fashion. First, a regression equation is constructed predicting psychological distress (y) among married women from their level of marital satisfaction, as measured by the Dyadic Adjustment Scale (x). Then, the mean level of psychological distress for unmarried women is substituted for y and the equation is solved to obtain the value for x needed to obtain y . Thus, among the married women

$$y = a + bx$$

yields

$$y = 60.06 - .20x.$$

Substituting the mean distress score for unmarried women (37.34) and solving for x yields a DAS score of 114.36. A formula found in Neter, Wasserman, and Kutner (1985) yields 95% confidence intervals for this figure of $\pm .60$. This estimated DAS score is modestly, but significantly higher than the mean DAS for the married women (111.79), $t(378)=2.67$, $p<.01$. Thus, it appears that, within this sample, married women need a better than average marriage to be as low in psychological distress as unmarried women, although the effect is not a large one.

Insert Table 3 here

Hierarchical Multiple Regression Analysis Examining the Contribution of Social Support To Women's Distress. A hierarchical multiple regression analysis was conducted to assess the contributions of key variables to the women's level of psychological distress. Psychological distress was the dependent measure with history of cancer, marital status, time since cancer diagnosis, and spouse and female relative support variables as predictors. We sought to utilize the entire sample for this analysis, but this required a solution to the problem of women without a history of cancer not having scores for the variable of Time Since Diagnosis, and unmarried women not having scores for the spouse support variables. These are important considerations. On the average, the women in our sample were relatively long-term survivors of cancer, with a mean length of time since diagnosis of 8.26 years and a standard deviation of 6.51 years. Clearly, we could not consider never having been diagnosed with cancer as 0 time since diagnosis: presumably there is an immediate increase in distress following a diagnosis, but this effect might dissipate with time. Similarly, our analyses had already shown that women in unsatisfactory marriages were worse off than unmarried women, and we could not assume that being unmarried was equivalent to having a husband and perceiving no positive or negative support from him.

Cohen and Cohen (1983) can be used to suggest a solution to this problem using nonsense coding of Time Since Diagnosis for women without a diagnosis of cancer and of spousal support for the unmarried women and dummy coding of breast cancer and marital status. It does not matter what Time Since Diagnosis is assigned to women who have not been diagnosed with cancer if we consider this variable only in interaction with Breast Cancer Status coded 0 for never diagnosed and 1 for having had a diagnosis. Similarly, it does not matter what scores for support from husbands are assigned to unmarried women if we consider these variables only in interaction with Marital Status coded 0 for unmarried and 1 for married.

As a first step in a multiple regression analysis, we entered the demographic variables: age, cancer status, marital status, and the modified time since diagnosis x cancer

status variable. As can be seen in Table 4, only 2% of the variance was accounted for by this model, with cancer status and time since diagnosis significantly contributing to distress. In the next step we entered the support variables: female relative and the modified spouse support x marital status variables. As can be seen in Table 4, there was a significant increase in the amount of variance accounted for by the model, but the only variable making a significant independent contribution to psychological distress was unsupportive behaviors from spouses.

Insert Table 4 here

Differences Between Spouses And Sisters As Sources Of Cancer-Specific Support.

Table 5 presents means and standard deviations of married women's ratings of their spouses and their sisters at risk for cancer as providers of cancer-specific support, distinguishing between satisfactorily and unsatisfactorily married women. A series of 2x2x(2) ANOVAs were conducted, with history of cancer and marital satisfaction as the between-subjects independent variables, and husband-versus-sister as the within subject variable for each cancer-specific support variable. In terms of discussions about cancer and cancer risk, there were significant main effects for marital satisfaction, $F(1,251)=4.83$, $p<.05$, with women in satisfying marriages reporting more discussions than women in dissatisfied marriages. A significant within-subject effect for source of support, $F(1,251)=6.25$, $p<.05$, reflected the marital relationship overall being the site of more discussions. It is notable that there was not a significant interaction between marital satisfaction and source of support. Instead, the only significant interaction was between cancer status and source of support, $F(1,251)=3.76$, $p<.05$. Follow-up paired t-tests revealed that women with a history of cancer reported discussing their risk of cancer more

with their spouses than with their sisters $t(125)=-3.61$, $p<.001$, while those without a history of cancer did not differ in the frequency of discussions with spouses and sisters.

Regarding satisfaction with discussions about cancer, women with a history of cancer $F(1,217)=6.96$, $p<.01$, and who were in a satisfying marital relationship $F(1,217)=13.37$, $p<.001$, were significantly more satisfied with discussions about cancer regardless of whether the discussions were with their spouse or their sister. There were no significant interaction effects found between marital satisfaction and source of support.

When examining the importance women place on opinions regarding ways to reduce cancer risk, main effects were found for marital satisfaction, $F(1,246)=9.91$, $p<.01$, and source of support, $F(1,246)=34.54$, $p<.001$. However, these effects need to be interpreted in light of the interaction found between marital satisfaction and source of support, $F(1,246)=16.10$, $p<.001$, and history of cancer and source of support, $F(1,246)=6.86$, $p<.01$. A main effect suggested that for women with a history of cancer, $t(121)=-7.18$, $p<.001$, and without such a history, $t(140)=-4.13$, $p<.001$, spouses' opinions were significantly more important than their sisters'. However, the interaction effect revealed that only women in satisfying marriages actually reported that their spouses' opinions regarding reducing risk were more important than those of their sisters, $t(169)=-8.88$, $p<.001$.

Main effects were also found for marital satisfaction, $F(1,248)=9.80$, $p<.01$, and source of support, $F(1,248)=28.05$, $p<.001$, when examining the importance women place on their support providers' opinions regarding getting genetic testing for risk of breast and ovarian cancer. Again, however, these effects must be qualified by a significant interaction between marital satisfaction and support provider, $F(1,248)=6.64$, $p<.05$. Also again, paired t-tests indicated that only women in satisfying marriages reported that their spouses' opinions regarding genetic testing were significantly more important than those of their sisters, $t(171)=-7.17$, $p<.001$.

Insert Table 5 here

Discussion

The results of the present study have both substantive and practical implications, and the manner in which marital satisfaction and spousal support were considered in the context of a sample in which not all women were married has broader methodological and theoretical implications. Yet, before considering these implications, the limitations of this study should be reiterated. This is a cross-sectional study of a self-selected and socially advantaged sample of women at high risk for breast and ovarian cancer, assessed at a point at which they knew genetic testing would soon be available. There have been other indications that persons who participate in genetic studies, and who seek genetic testing, are socially advantaged, and that they self-select for ability to cope with the potentially threatening results of genetic testing (Codori, Hanson, & Brandt, 1994; Codori, Slavney, Young, Miglioretti, & Brandt, 1997; Coyne, Weber, & Sonis, 1999). Our largely middle-aged sample tended to be married, and the women who were married tended to be in satisfactory first marriages of relatively long duration. The sample was also high in education and income. It could be that their marital quality and high levels of support are critical determinants of their lack of distress or morbidity despite their familial risk for cancer, but other resources could account for their positive adjustment. As genetic testing becomes more widespread in the community, it will be important to compare our registry sample of women to women in community clinical settings who seek testing, with respect to social support as well as other variables. Most of what is known about psychosocial aspects of genetic testing comes from studies of women who have enrolled in hereditary cancer registries, and who receive testing in the context of research protocols approved by institutional review boards. There has been concern that, as testing becomes more

widespread, there will be important shifts in who is offered genetic testing, who receives it, and under what circumstances (Coyne et al., 1999; Coyne et al., 1998). Comparisons between registry samples, such as the present one, and community samples are important, not only for determining the comparability of psychosocial resources among the two groups, but also for establishing whether the relations among variables observed in registry samples actually explain the relative well-being of these women as a group.

For the purposes of the present discussion, the women's relatively low mean levels of distress and high levels of marital satisfaction in our sample should be taken into account in interpreting correlational and regression analyses. When we discuss women as having greater distress as a result of perceiving less social support, we are interpreting findings from a sample in which overall levels of distress are low. We have noted that even among maritally-dissatisfied women, psychological distress remained below the clinical cutpoint on the HSCL-25. Also, the marital stability and relatively high marital satisfaction of these women should be kept in mind in discussing marital variables. In dividing the married women into satisfied and dissatisfied groups, we were careful to use established cutpoints for marital adjustment. Had we utilized a median split, we would have considered many women as maritally dissatisfied who were decidedly not so by normative standards.

We applied some regression techniques that allowed us to make comparisons between married and unmarried women that took into account the marital satisfaction of the married women. However, we had no equivalent measure for the unmarried women. It might seem that the unmarried women's satisfaction with their marital status should also be taken into account. Yet, the one study we could find that assessed unmarried women's satisfaction with their status failed to find it to be related to their well-being (Gove & Zeiss, 1987). Apparently, satisfaction with not being married among the unmarried is not analogous to marital satisfaction among married women.

However, even keeping in mind potential limitations on the generalizability of these results, some important points can be made. In much of the social support literature, there

has been an implicit assumption that people have a set amount of interpersonal needs that can be satisfied in different patterning of relationships and with support from different persons. Historically, this has been termed the "fund of sociability" idea (See Weiss, 1968, for a review). On this basis, it might be assumed that women who lacked a spouse, or whose spouse was unsupportive, would seek compensatory support from female relatives. Plausible though this notion may be, we found no evidence for it, and considerable evidence against it. Indeed, support from the spouse was positively correlated with support from a close female relative, and women in satisfactory marriages actually perceived more support from female relatives than did unmarried women or women in unsatisfactory marriages. Women in dissatisfied marriages still discussed their risk status with their husbands more than with female relatives. There are a number of possible interpretations of these findings. It may be that perception of support is more of a person variable than generally recognized, either as a result of personality determining perception of support or distress mainly determining perception of support, rather than the perceived availability of support affecting level of distress. This intrapersonal interpretation has been favored by Sarason, Pierce, and Sarason (1990), among others. Alternatively, it could be that marital difficulties and accompanying distress alienate other sources of support, or reduce the women's access to it. Finally, satisfactory marriages may facilitate positive social involvement outside the marriage. Such competing hypotheses need to be evaluated using sources of data other than the women themselves, and, notably, others' perceptions of how available and supportive they are of the women, and how frequent and satisfying their interactions are with the women.

In terms of cancer-specific support and decision-making processes, both sisters and husbands are important and involved in discussions with these women. However, husbands appear to play a somewhat more important role than female relatives, despite the women's shared familial risk status. As in the general patterning of findings in this study, this statement needs to be qualified with respect to marital adjustment. Women in

unsatisfactory marriages discuss their risk status more with their husbands than with female relatives, although their husbands have diminished influence.

Our sample consisted entirely of women deemed at high risk for breast cancer on the basis of personal and familial history. We examined both personal history of cancer and length of time since diagnosis as influences on well-being, but social support processes seemed to be more important influences on well-being. One might be tempted to argue that, because all women in the sample were at high risk for cancer, we underestimated the influence of this status on well-being. Yet, it must be kept in mind that the sample was low in distress relative to various comparison samples (Coyne et al., 1998). Unless we wish to argue that high-risk status *per se* somehow reduces distress, we need to acknowledge the importance of psychosocial influences on these women's well-being. In particular, husbands proved to be primary influences on the women's distress levels, and primary sources of cancer-specific support. Within the sample as a whole--considering both married and unmarried women--unsupportive behavior by the husbands was the only independent connection between social support processes and distress, despite other significant bivariate relations between support and distress. Finally, married and unmarried women had similar levels of distress, but additional analyses showed that married women had to have modestly better than average marriages to be equivalent to unmarried women.

Implications for Application and Public Policy.

These results have a number of practical implications for efforts to educate and counsel high-risk women for the prospect of genetic testing for risk of breast and ovarian cancer in research settings. It appears that husbands of these high-risk women are key influences on their well-being and providers of cancer-specific support, as well as active participants in the women's decision-making processes. The women should be given opportunities for involving husbands in the pre-education and counseling process, to ensure that the men's participation in the women's decision-making is informed and appropriate. It has previously been recognized that genetic testing is a family, as well as an

individual, issue, but much of the emphasis has been on blood relatives who share a high-risk status, and for whom other family members' test results are potentially informative of their own risk status. However, our data indicate that husbands are at least as influential as the women's closest at-risk female family member. Our data were collected prior to genetic testing actually being made available to these women. Once results begin to be received by the women and their family members, husbands could become even more important.

Women may be less able to seek support from female relatives who are struggling with their own discovery that they have an altered gene associated with heightened risk for cancer. Furthermore, women who find that they do not have such an altered gene may still be distressed about the process of genetic testing, but feel guilty and ineligible to compete for support with female relatives who are found to have an altered gene. Clinical experience with genetic testing for Huntington's disease suggests that support from close, but not genetic-related, relatives can be crucial at the point of risk disclosure. It is reassuring that the husbands of the high-risk women in our sample are already involved as support providers. However, all of these points need to be qualified with reference to women in the study being self-selected members of a hereditary cancer registry. The results we have presented here and the implications we have drawn may not apply to women from the community expressing an interest in genetic testing.

Table 1Demographic Characteristics by Breast Cancer and Marital Status.

	History of Cancer		No History of Cancer	
	Married (N=182)	Not Married (N=32)	Married (N=212)	Not Married (N=47)
Age	50.09 (10.56)	60.32 (12.41)	45.27 (10.70)	49.99 (16.38)***
Percent white	98.9%	96.9%	97.6%	97.9%
Percent Christian	68.3%	83.9%	80.2%	76.6%*
Percent completed some college	81.9%	67.7%	81.6%	83.0%
Percent employed outside home	62.6%	53.3%	65.4%	61.7%
Household income	\$53,600	\$25,000	\$53,900	\$33,900*
Percent first marriage	81.7%	NA	81.3%	NA
Percent ovarian cancer diagnosis	3.4%	10.0%	NA	NA
Years since breast cancer diagnosis	7.55 (5.79)	12.54 (8.79)	NA	NA
Percent in remission	89.9%	92.6%	NA	NA

* p < .05, ** p < .01, *** p < .001

Table 2

Bivariate Pearson Correlations of Age, Distress and Support Variables for
Married Women

	1	2	3	4	5	6
1. Age	1.00	-.14	-.12	.00	-.16	.03
2. Hopkins	.01	1.00	-.22**	.30***	-.22**	.14
3. Spouse Support	-.17*	-.08	1.00	-.51***	.36***	-.14
4. Spouse Unsupportive	.05	.25***	-.53***	1.00	.00	.21*
5. Female Relative Support	.10	-.16*	.21**	-.06	1.00	-.35***
6. Female Relative Unsupportive	-.09	.13	-.02	.21**	-.54***	1.00

Note: above the diagonal are women with a history cancer and below are women without such a history.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 3

Effects of Marital Status/Satisfaction on Distress and Social Support

	Not Married (N=70) Mean (SD)	Distressed Marriage (N=124) Mean (SD)	Satisfactory Marriage (N=248) Mean (SD)	df	F
Hopkins	37.10 ^a (9.59)	41.95 ^b (10.35)	35.79 ^a (7.64)	(2,445)	20.06***
Female Relative Support	7.59 ^a (3.92)	7.85 ^{ab} (2.95)	8.54 ^b (3.03)	(2,400)	3.06*
Female Relative Unsupport.	.21 (.64)	.28 (.71)	.16 (.56)	(2,394)	1.39
Spouse Support	NA	7.53 (2.93)	9.84 (1.73)	(1,356)	91.01***
Spouse Unsupportive	NA	.79 (1.03)	.13 (.42)	(1,345)	70.92***

* p < .05, ** p < .01, *** p < .001

Table 4

Hierarchical Regression Examining Predictors of Psychological Distress for Women at Risk of Breast and Ovarian Cancer.

Psychological Distress (N=356)		
Predictor Variables	Change in R ²	B
Step 1: Demographic Variables	.02	
Age		-.03
Breast Cancer Status		.20**
Marital Status		-.03
Time Since Diagnosis		-.17*
Step 2: Support Variables	.09***	
Female Relative Positive Support		-.11
Female Relative Negative Support		.06
Spouse Positive Support		.14
Spouse Negative Support		.29***
Full Predictor Set	R ² = .11***	

* p < .05 ** p < .01 *** p < .001.

Table 5

Mean Ratings of Cancer Specific Support Received from Spouses and Sisters for Women in Distressed Marriages and in Satisfying Marriages.

Likert Scale Items	Women in a Distressed Marriage		Women in a Satisfying Marriage	
	Spouse M (SD)	Sister M (SD)	Spouse M (SD)	Sister M (SD)
Discuss breast cancer with him/her	2.65 (.96)	2.58 (.93)	2.96 (.86)	2.68 (.90)***
Satisfaction with these discussions	2.94 (.92)	3.00 (1.02)	3.33 (.81)	3.27 (.85)
Importance of his/her opinion in your getting BRCA1 testing	2.49 (1.20)	2.24 (1.28)	3.13 (1.05)	2.42 (1.24)***
Importance of his/her opinion in making decision about reducing risk	2.59 (1.17)	2.43 (1.23)	3.32 (1.03)	2.51 (1.18)***

Note: N ranges from 65-84 for paired t-tests of women in distressed marriages, and from 156 to 172 for those women in satisfying marriages.

p>.01 *p>.001

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Distress and Psychiatric Morbidity Among Women From High-Risk Breast and Ovarian
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Abstract

This study assessed psychological distress and psychiatric disorder in high-risk women enrolled in a hereditary breast and ovarian cancer registry, and it evaluated the concordance between self-report data and interview-based psychiatric diagnosis. A sample of 464 women both completed the Hopkins Symptom Checklist-25 and were interviewed using modules of the Structured Clinical Interview for DSM-IV (SCID). Level of psychological distress and the prevalence of psychiatric disorder were low, and in the range that would be expected for a sample of community-residing women. Screening proved inefficient: less than 10% of distressed women met criteria for a clinical disorder. High-risk women seeking genetic testing in research settings may not require extensive psychological screening and diagnostic assessment. Caution is expressed about possible self-selection biases in women enrolled in hereditary cancer registries.

Distress and Psychiatric Morbidity Among Women

From High-Risk Breast Cancer Families

The mapping of the human genome and the cloning of genes that convey risk for adult onset diseases raises the possibility of increasingly widespread genetic testing. Consideration of the presumed benefits of genetic testing needs to be balanced by concerns about the psychological and psychiatric morbidity that could result from individuals being provided with potentially devastating information about future threats to their health. Testing will result in many individuals being burdened by the knowledge that they have an increased probability of developing a life-threatening disease long before its likely onset, and yet options for managing this risk are currently limited. Moreover, individual testing results may reveal that other family members are likely to have an inherited susceptibility to cancer, and this could prove to be an additional psychologically-threatening prospect.

The need to understand psychosocial issues in genetic testing became more pressing with the cloning of the genes BRCA1 (Miki et al., 1994; Tavtigian et al., 1996) and BRCA2 (Wooster & Stratton, 1995), alterations of which are associated with many cases of early-onset breast and ovarian cancer. BRCA1 mutations confer an increased risk for breast, ovarian, and prostate cancers. The lifetime risk of breast cancer for a woman with a BRCA1 mutation is in the range of 50-85%. In women already diagnosed with a unilateral breast cancer, there is also an increased risk for developing disease in the contralateral breast. The risk of ovarian cancer approaches 20-40% by age 80. BRCA2 mutations are similar to BRCA1 mutations in conferring a 50-85% lifetime risk for breast cancer in women. The risk for ovarian cancer is lower than that associated with BRCA1, approximately 15-20% over the lifetime. BRCA2 mutations also appear to be associated

with other cancer risks, possibly including pancreatic cancer and other as yet undetermined sites (Ford et al., 1998).

It is estimated that as many as 1 in every 1000 persons carry an altered gene associated with susceptibility to breast and ovarian cancer (Ford & Easton, 1995). Options for women who test positive for an altered gene include increased surveillance, prophylactic mastectomy and/or oophorectomy, and, for some, participation in a chemoprevention trial. None of these measures have proven to be entirely efficacious, and all have known limitations (Burke et al., 1997; King, Rowell, & Love, 1993). There has been a recent finding from a retrospective study that prophylactic mastectomy may reduce the incidence of breast cancer and death from breast cancer among high-risk women by as much as 90% (Hartmann et al., 1999). However, a closer look at this study highlights the uncertainty facing carriers of mutations of BRCA1 and BRCA2 in making decisions about how to manage their risk (Eisen & Weber, 1999). First, it is unclear to what extent the benefits observed in a heterogeneous sample of at-risk women extend to carriers of mutations of BRCA1 and BRCA2. It is likely that only a minority of the women in the Hartmann et al. (1999) study were mutation carriers, perhaps as few as 10% (Couch et al., 1997). Secondly, in this study, 639 women electing prophylactic surgery only resulted in a reduction of deaths from an expected 20 to an observed 2. Saving 18 lives is important, but the awareness that another 621 women would probably have survived without electing disfiguring surgery may make the choice of prophylactic surgery unacceptable to many women (Eisen & Weber, 1999).

Although genetic screening for risk of breast and ovarian cancer has become available commercially, it is still considered most appropriate for women who are already considered at high risk based on family history. This is because negative test results are not particularly informative for women without a known altered gene accounting for breast cancer in their families. Women with positive family histories have expressed considerable interest in being tested (Jacobsen, Valdimarsdottir, Brown & Offit, 1997; Lerman, Seay,

Balslem & Audrain, 1995; Lerman et al., 1997). To varying degrees, these women will have had experiences with cancer among their close female relatives, and their personal risk will have been made salient for them as they confront the opportunity to be tested. Many will already have a history of breast or ovarian cancer, and they will be seeking testing to determine the risk of cancer in the contralateral breast or in the ovary, or to determine if their cancer is associated with an altered gene carrying heightened risk for other family members. Other women seeking testing will not have such a personal history of cancer, but, on the basis of their high-risk status, already assume that they have the altered gene, and that this is tantamount to having been diagnosed with cancer (Geller et al., 1995).

One key issue is the extent to which high-risk women's existing level of distress or vulnerability to major depression or other psychiatric disorders might impair their ability to become educated, make an informed choice about testing, and utilize their test results to manage their risk of cancer. There is now one study indicating that genetic testing does not lead to psychological distress, even when patients learn they have a mutation associated with heightened risk of cancer (Lerman et al., 1996). This finding is reassuring, but the research is limited to a distinct group of men and women who had a known genetic basis for the cancer in their families, and who had been participating in genetic studies for a long time. This research report also combined data from men and women in these high-risk families. Women, in general, have higher levels of distress than men, and they can also be expected to be more affected than men by anticipation of testing and receipt of information that they carry a gene associated with heightened risk for breast cancer. In the absence of much experience with women seeking genetic testing for risk of breast cancer, we are forced to draw on other relevant research such as women anticipating a biopsy and women who have been diagnosed with breast cancer. Also relevant are studies of individuals learning their risk status for illnesses such as Huntington's disease (HD) and HIV.

There have been indications that some women having a family history of breast cancer breast are psychologically distressed (Kash, Holland, Halper, & Miller, 1992;

Lerman & Schwartz, 1993; Valdimarsdottir et al., 1995). Other studies suggest that women who awaiting a biopsy because of suspected breast cancer are psychologically distressed (DeKeyser, Wainstock, Rose, Converse, & Dooley, 1998; Hobfoll & Walfisch, 1984). Moreover, several investigators have reported that women with confirmed diagnoses of cancer have elevated rates of clinical depression (e.g., Derogatis et al., 1983; Fallowfield, 1990; Goldberg et al., 1992; Hopwood, Howell, & Maguire, 1991; Maguire et al., 1978). In contrast, some investigators have reported low levels of psychological distress and clinical depression among women with breast cancer (e.g., Plumb & Holland, 1981; Silberfarb, Maurer, & Crouthamel, 1980; Worden & Weissman, 1977). There have been historic changes in the social and health care milieu within which breast cancer is diagnosed and treated (Andrykowski et al., 1996) which may decrease the associated distress and psychiatric morbidity. Yet, the lack of consistent findings in these studies is also undoubtedly due, in part, to the basic methodological weaknesses inherent in much of this research. Specifically, many of these studies involved small samples of women assessed either directly after diagnosis and surgery, or during advanced stages of the illness (e.g., Goldberg et al., 1992; Hopwood et al., 1991; Maguire et al., 1978; Pinder et al., 1993; Silberfarb et al., 1980). Additionally, researchers have typically relied on self-report assessment in determining psychiatric morbidity (e.g., Goldberg et al., 1992; Hopwood et al., 1991; Pinder et al., 1993). There is a need to distinguish between self-reported distress and interview-based diagnoses of psychiatric disorder (see Coyne, 1994, for an extended discussion). Elevated scores on self-report measures of distress, such as the Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977), Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), and various versions of the Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenuth, & Covi, 1974; Hough, Landsverk, Stone, & Jacobson, 1982), consistently provide overestimates of the rates of diagnosable psychiatric morbidity. However, despite clarification of the distinction between distress and clinical depression (Massie & Popkin, 1998), the confusion of the two

remains widespread in the psycho-oncology literature (For recent examples, see Keogh, O'Riordan, McNamara, Duggan, & McCann, 1998; Zittoun, Achard, & Ruszniewski, 1999) and the genetic testing literature as well (Lawson et al., 1997).

Studies of genetic testing for risk of HD and serological testing for HIV suggest that distress and development of psychiatric disorder are not necessary consequences of receipt of positive test findings. Negative emotional reactions may be transient except for some persons who were distressed before testing, or who had a past history of depression (Perry, Jacobsberg, Fishman, Frances, 1990). As in other contexts, current distress may predict later distress (Cramer, 1994; Kaplan, Roberts, Camacho-Dickey, & Coyne, 1987), and a history of depression is one of the most reliable predictors of future risk of depression (Belsher & Costello, 1988; Coyne, Pepper, & Flynn, 1999). Thus, the few studies that included interview-based diagnoses with representative populations have reported low rates of current, but higher rates of past psychiatric morbidity (Maunsell, Brisson, & Deschenes, 1992; Silverfarb et al., 1980). These studies underscore the importance of assessing both current, as well as past, psychiatric morbidity, particularly because women with a past psychiatric history who do not have a current disorder may represent a subpopulation vulnerable to negative reactions to testing.

In summary, on an a priori basis, one might assume that anticipation of genetic testing for risk of breast cancer and receipt of results will entail risk of distress and psychiatric disorder. High-risk women suitable for testing may already have elevated distress and rates of psychiatric disorder that would interfere with education and informed consent. On the other hand, review of some relevant literatures raises the possibility that the risk may not be as great as anticipated. With the advent of more widespread testing, the question of the psychological status of women seeking testing should not be left to conjecture (Botkin et al., 1996; Lerman, 1997). Knowledge of the rates of distress and psychiatric disorder is vital to ascertaining the need for psychological screening, for designing educational and counseling programs, for estimating the need for auxiliary mental

health services, and for evaluating the incremental distress and morbidity occasioned by positive test findings.

The present study examined rates of psychological distress and psychiatric morbidity among a sample of women who were considered at high risk for breast and ovarian cancer on the basis of personal and family history. They had been enrolled in the registry of the Hereditary Breast and Ovarian Cancer Study conducted by the University of Michigan and then the University of Pennsylvania Cancer Center registry. Some of these women were deemed at high risk, and were eligible for enrollment in the registry because they already had a diagnosis of breast cancer or ovarian cancer and had at least one other family member who had been diagnosed with one of these cancers. These women have a greater likelihood of contralateral breast cancer and/or ovarian cancer than women without a family history. Other women in this study had not been diagnosed with breast or ovarian cancer themselves, but were eligible for enrollment in the registry because they had at least two relatives who had been diagnosed with one of these forms of cancer.

The women were assessed at a time when they were anticipating the offering of genetic testing to them which could reveal whether they had an altered gene associated with increased risk of cancer. The Hereditary Breast and Ovarian Cancer Study was originally conceived primarily as basic research, not as a clinical service, but, by the early 1990s, it became possible to perform linkage analyses with a few families so that it could be determined whether a particular member of the family had an increased risk of cancer. Experience disclosing the results of linkage analyses to some of these families highlighted the complex psychosocial issues involved in making such information available (Biesecker et al., 1993). Moreover, it was apparent at the time that a gene associated with increased risk of breast and ovarian cancer would soon be isolated, and more widespread testing would then become possible. A research project was initiated examining psychosocial issues associated with genetic testing in the Hereditary Breast and Ovarian Cancer Study sample of women. The data reported in this paper are derived from baseline assessments obtained

from these women in the year after the announcement that a strong candidate for the breast and ovarian cancer susceptibility gene, BRCA1 had been identified (Miki et al., 1994), and when the offering of genetic testing was widely expected to be imminent. Moreover, there was the anticipation that BRCA1 would account for more familial breast cancer than actually proved to be the case, and that genetic testing would provide more information to these women than it has (Couch et al., 1997).

The first objective of this study was to assess general psychological distress, cancer worries, and current and past psychiatric disorder in women enrolled in a hereditary cancer registry. This is the first study using interview-based diagnosis to supplement self-report data in evaluating high-risk women. A second objective was to evaluate the concordance between self-report data and interview-based current and past psychiatric diagnoses. Self-report screening instruments are economical and readily administered, but tend to have the disadvantage of low specificity as a means of identifying psychiatric cases (Fechner-Bates, Coyne, & Schwenk, 1994). Moreover, the relationship between self-reported distress and depression is not fixed and constant across populations. For instance, a large-scale epidemiological study of adolescents found that the prevalence of elevated scores on the CES-D (Radloff, 1977) was so high (48%), and the prevalence of depression so low (2.5%), that there was little chance-corrected agreement between the CES-D and a diagnosis of depression (Roberts, Lewinsohn, & Seeley, 1991).

The inclusion of both self-report measures and diagnoses based on semi-structured interview allows us to examine the performance of the self-report measures for possible use as the first stage of a two-stage strategy for identifying psychiatric morbidity. Furthermore, this comparison allows us to evaluate the conclusions about anxiety and depression in this population that are being made on the basis of self-report data (Lerman et al., 1996, 1998). The relationship between an elevated score on a measure of distress and a clinical diagnosis can be summarized in terms of the sensitivity and specificity of the self-report measure (Fletcher, Fletcher, & Wagner, 1988; Zarin & Earls, 1993). Sensitivity refers to the

proportion of persons with a particular diagnosis who also score above a cutpoint on the self-report measure, and who are, therefore, correctly identified as disordered by the measure. Specificity refers to the proportion of persons without a disorder who score below the cutpoint. For the purposes of evaluating the use of a self-report measure as a screening instrument, an additional summary statistic is informative, the positive predictive value. This expresses the probability that a patient obtaining a positive screening score will have the disorder, and depends upon the prevalence of the disorder, as well as the specificity and sensitivity of the test (Fletcher et al., 1988).

The substantial number of women in our sample who had a history of breast or ovarian cancer gave rise to a final, auxiliary aim of this research. These women were relatively long-term survivors of cancer. As we noted, much of what is known about adjustment and psychiatric morbidity of persons affected by cancer comes from samples biased toward elevated levels of distress and depressive and anxiety disorders. Our large sample allowed us to examine whether these past results hold for women who have not been recently diagnosed, or who, as a group, are not typically in the midst of active treatment or the terminal stages of the disease.

Method

Sample and Recruitment Procedure

Women participating in the study were drawn from the registry of the Hereditary Breast and Ovarian Cancer Study conducted by the University of Michigan and the University of Pennsylvania Cancer Center. In August 1995, these women were sent a newsletter informing them of a study aimed at examining the psychological factors associated with anticipating and receiving genetic testing. The newsletter gave them the opportunity to decline further solicitation concerning this study. Questionnaire packages and consent forms were then mailed to their homes. A cover letter was included explaining to participants that, upon receipt of their questionnaires, a researcher would contact them to arrange a telephone interview. The letter emphasized that the information provided would be kept confidential.

If women did not respond to this mailing with an acceptance or declining of participation in the study, a follow-up letter was sent, and, if there was still no response, attempts were made to reach the woman by telephone. If women elected to pursue the next phase of the study, an appointment was arranged for a telephone interview. When participants were contacted by telephone, they were again explained the voluntary nature of participation. On average, the questionnaires required 30 minutes to complete, and the telephone interviews lasted approximately 45 minutes. The interviews were conducted by well-trained interviewers with graduate training in clinical psychology, social work, or nursing. Of the 633 eligible women who were mailed questionnaires, 477 (75%) returned them. Of the 156 women who did not return the questionnaires, 54 declined participation and 102 did not return a questionnaire despite efforts to reach them by follow-up letter and telephone call. Our sense is that for the most part, this latter group had simply been lost to the registry, rather than representing passive refusals. Of the 477 women who returned a questionnaire, 464 received a telephone interview. The final sample consisted of 211 women with a previous history of breast or ovarian cancer, and 253 who did not have such a history.

Measures

Psychological distress. The 25-item version of the Hopkins Symptom Checklist (HSCL-25) was used to assess psychological distress. The scale includes uses 10 items from the HSCL-90 anxiety cluster, 13 items from the depression cluster, and two additional somatic symptoms (poor appetite; difficulty falling asleep or staying asleep). The same items also appear with inconsequential differences in wording on the Symptom Checklist 90 (SCL-90; Derogatis & Cleary, 1977). Hesbacher, Rickels, Downing, and Stepansky (1978) found that the HSCL-25 correlated highly with the standard 58-item version Hopkins Symptom Checklist (Derogatis et al., 1974). The HSCL-25 has been widely used for the psychiatric screening of medical patients (Fink et al., 1995), and with a cutoff of 44 for caseness, Hough et al. (1982) found that the HSCL-25 was comparable or superior to the CES-D (Radloff, 1977) in detecting psychiatric disorder, depending on the

criterion employed. There are extensive data using this scale with healthy, physically ill, and psychiatric samples where adequate rates of reliability have been reported (Cohen, Coyne, & Duvall, 1993; Coyne, Kessler, Tal, & Turnbull, 1987; Coyne & Smith, 1991; Cranford, Coyne, Sonnega, & Nicklas, 1998; Hesbacher, Rickels, Morris, Newman, & Rosenfeld, 1980; Pepper, Coyne & Cohen, 1996). Consistent with past studies, coefficient alpha for the HSCL-25 was found to be .91.

Depression Screening Questions. Additional self-report screening questions for depression were taken directly from the questions assessing two-week mood disturbance and associated impairment from the Structured Clinical Interview for DSM-IV (SCID-IP; First, Spitzer, Williams, & Gibbon, 1995). One question inquired whether, in the past six months, there had been two weeks of depressed mood most of the day, nearly every day. Another question inquired whether there had been two weeks of markedly diminished interest or pleasure in all, or almost all, activities. If the answer was affirmative to either of these questions, a follow-up question inquired whether there had been treatment or interference in role functioning. Rost, Burnam, and Smith (1993) had previously reported sensitivity in excess of .80 and specificity in excess of .90 for the two questions with respect to a simultaneously obtained diagnosis of major depression using the Diagnostic Interview Schedule (DIS; Robins, Helzer, Croughan, & Ratliff, 1981). While these figures suggest some promise for these questions as a means of screening for depression, they may have been inflated by their direct correspondence to the questions in the DIS. Unlike the Structured Clinical Interview for DSM-IV (SCID; First et al., 1995) used in the present study, the DIS is basically a lay-interviewer administered questionnaire, and does not allow for interviewer probes of responses (Coyne, 1994).

Breast Cancer Worries. Two 5-point Likert-style items assessed how often women worry about developing breast cancer, and the extent to which these worries interfere in their lives (1 = Not at all, 5 = Very much). These items have been used in a number of studies and have been found to be positively related to both general psychological distress

and to cancer screening adherence (Lerman et al., 1991; McCaul, Branstetter, O'Donnell, Jacobson, & Quinlan, 1998; Schwartz et al., 1995; Stefanek & Wilcox, 1991). These items were only administered to women without a history of breast or ovarian cancer.

Interview-based measures of psychiatric morbidity. Semi-structured interviews were conducted to assess current and past history of depression, anxiety, and alcohol use. Because of its modular construction, the SCID can be adapted for use in studies in which only a particular diagnosis is of interest (First et al., 1995). The mood disorders, anxiety and alcohol use modules of the SCID were utilized in this study. The administration of the SCID was done by telephone because many of the participants were from out of state. Previous studies have shown the concordance of telephone-administered diagnostic interviews with face-to-face interviews for assessment of depression (Baer, Brown-Beasley, Sorce, & Heenriques, 1993; Kendall, Neale, Kessler, Heath, & Eaves, 1992; Potts, Daniels, Burnham, & Wells, 1990; Wells, Burnam, Leake, & Robins, 1988). Also, Slutske et al. (1998) recently showed that the reliability and validity of alcoholism diagnoses and symptoms by telephone assessment is as good as what is obtained in face-to-face interviews. Concurrent with the present study, we conducted a reliability study comparing interviewer's diagnoses and ratings of diagnosis and symptoms of depression to independent raters using 28 audiotapes of telephone assessments. There was 100% agreement for diagnosis, and 97% agreement for specific symptoms.

Results

Basic Demographics

As can be seen from Table 1, there were no differences between women with and without a history of cancer for the demographic variables, except that women with a history were significantly older. As a whole, the women were in their late forties, and they are predominantly White (98.1%), Christian, married, and have an average of two children. One striking characteristic of this group is their high level of education and income. Most women had at least some college, worked outside the home, and had an annual income that

exceeds \$54,000. These results are consistent with previous findings that women who seek genetic testing are generally well-educated and have a higher social economic status (Codori, Hanson, & Brandt, 1994; Kash, Holland, Osborne, Miller, & Rosenthal, 1997). On average, 8.24 years had elapsed (S.D.= 6.50) since the women with a history of cancer were first diagnosed with cancer, indicating that these women were long-term survivors of cancer. Among those who had a history of breast or ovarian cancer, 50% reported unilateral mastectomy, 20% reported bilateral mastectomy, and 17% reported oophorectomy. Among those who did not have histories of breast cancer or ovarian cancer, 1% reported bilateral mastectomy, and 18% reported oophorectomy.

Psychological Distress.

Table 2 presents findings concerned with self-reported psychological distress for the full sample, as well as for women with and without histories of cancer. As can be seen, there were no differences between the two groups on the HSCL-25, and both groups had a mean score below the clinical cut-point of 44. Overall, only 21% (C.I. 18-25%) of the women scored in the clinically distressed range. By way of comparison, these women are similar to primary medical care samples (Hesbacher et al., 1980) and nearly identical to women recruited for a recent clinical trial at other sites comparing alternative models of pretest education for BRCA1 testing (Audrain et al., 1997). However, the women in the present study are substantially lower in distress than wives of post-myocardial infarction patients (Coyne & Smith, 1991), persons living with a depressed person (Coyne et al., 1987), female congestive heart failure patients and wives of congestive heart failure patients (Cranford et al., 1998), and divorced women who do not have custody of their children (Santora & Hays, 1998).

Breast Cancer Worries.

Women who had never been diagnosed with cancer scored 2.88 (S.D. = .98) on the measure of breast cancer worries, and 1.65 (S.D. = .93) on the measure of how much these worries interfered with their lives. Although only 7.9% of the women endorsed the

lowest ("not at all") rating of how often they worried about developing breast cancer, most (58.9%) of the women reported that worries about cancer interfered with their daily lives "not at all." Worries and interference were correlated with each other, $r=.47$, $p<.001$, and with general psychological distress, $r=.31$, $p<.001$) and $r=.30$, $p<.001$, respectively. Further evidence that breast cancer worries were not a major source of distress and impairment can be obtained by using the results of a regression analysis to determine the correspondence of a score for breast cancer worries to a score on the Hopkins-25. Basically, this analysis involved regressing the HSCL-25 on breast cancer worries, and then using the resulting equation to determine the HSCL-25 score corresponding to mean score for breast cancer worries of the women in the current sample. In this manner, it was found that the mean score of 2.88 for breast cancer worries corresponds to a Hopkins-25 score of 37.5, which is well below the clinical cutpoint for the Hopkins-25.

Psychiatric Disorder.

Table 3 presents findings from interview-based measures of current and lifetime psychiatric morbidity, including depression, anxiety, and alcohol abuse. In the overall sample, only 5 women (1%; C.I. .1 to 2%) met criteria for current Major Depressive Disorder, 4 of whom had histories of cancer. These figures can be interpreted in light of a reported one-year prevalence of major depressive disorder among primary medical care patients ranging from 4.8 to 13.5% (Coyne, Fechner-Bates, & Schwenk, 1994, Katon & Schulberg, 1992) and a one-month prevalence of 2.9 % in community samples of women (Regier et al., 1988). Eighty-seven women (17%; C.I. 14-20%) were found to have a lifetime history of Major Depressive Disorder, 46 of whom (53%) had a history of breast or ovarian cancer. This can be compared to a lifetime prevalence of major depression in women of 8% in the Epidemiologic Catchment Area Study (Weissman et al., 1993) and 21% found in the National Co-Morbidity Study (Kessler et al., 1994). Thus, the lifetime prevalence of Major Depressive Disorder for these high-risk women was low and in the range that would be expected for a sample of community residing women of this age. One

woman with a history of cancer and one without this history met criteria for Dysthymic Disorder. One woman with a history of cancer and two without this history met criteria for Generalized Anxiety Disorder. Three women without a history of cancer met criteria for Mixed Anxiety and Depressive Disorder. Only one woman was found to have an alcohol abuse problem, and she did not have a history of cancer.

Performance of Screening Instruments.

Such a low prevalence of current major depression precludes screening instruments from being efficient in identifying cases. A score meeting or exceeding the clinical cut-point of 44 on the HSCL-25 yielded a sensitivity of 80%, a specificity of 80%, and a positive predictive value of 4% for depression. The respective values for the HSCL-25 with generalized anxiety as the criterion were 100%, 79%, and 3%. The respective values for the HSCL-25 with either depression or generalized anxiety as the criterion were 88%, 93%, and 7%. Women's self-report on a two-weeks mood disturbance screening question yielded a sensitivity of 60%, a specificity of 86%, and a positive predictive value of 5% for major depression. Little difference was found for including the requirement of a report of impairment for the 2-weeks mood disturbance in the form of seeking treatment or experiencing difficulties in interpersonal functioning. Overall, screening for psychiatric morbidity using a standard self-report measure would be a highly inefficient process in which most women would not screen positive, and the vast majority of those who screened positive would prove to be false positives in terms of psychiatric diagnosis.

Discussion

The high-risk women in this sample were remarkably free of psychological distress and psychiatric morbidity. These results held for women both with and without histories of cancer. Only the women without histories of cancer were assessed for cancer worries, but these women were found to have little interference of cancer worries in their daily lives. Despite their increased risk for breast and ovarian cancer, as well as their repeated exposure to cancer either in themselves or their relatives, these women compared well with women

drawn from other samples. They were comparable to, and--depending upon the comparison sample-- had even lower rates of psychological distress and psychiatric disorder than women drawn from primary medical care and community settings. Thus, it appears that as these high-risk women approached the process of counseling, education, and decision making about testing, they were not, as a group, impaired by their psychological state.

Our second objective was to examine the performance of self-report measures for the purposes of screening for clinical disorder. There is an absence of past data concerning the relations between distress and psychiatric morbidity among such high-risk women. We found that a low score on a standardized measure of distress was a good indicator that the women were not suffering from major depression or from an anxiety disorder. Yet women scoring above a standard cut-point were unlikely to meet criteria for a clinical disorder, indicating that the measure had exceptionally low positive predictive value. The positive predictive value of 4% for major depression in the present study is still a fraction of the 15-30% obtained in primary care populations (Fechner-Bates et al., 1994; Hough et al., 1982). Indeed, a woman screening positive for depression on the self-report measure in the present sample would no more be likely to be depressed than a randomly selected, unscreened woman in the general medical population (Coyne et al., 1994, Katon & Schulberg, 1992). The performance of these instruments in detecting disorder in this study was constrained by the low prevalence of disorder (Elwood, 1993), and it is unlikely that any modifications of the screening instrument would result in substantially improved performance. Practically speaking, these results demonstrate that, as a group, the women do not require extensive psychological screening and diagnostic assessment. The routine use of screening instruments would be inefficient, in that less than 10% of the women who were distressed would meet criteria for a clinical disorder.

The results obtained in this study have implications for the interpretation of other studies of the adjustment of high-risk woman who are anticipating, or who have received,

results of genetic testing. Such studies utilize self-report measures of distress as indices of anxiety and depression, yet elevated scores on such instruments may be even less indicative of psychiatric disorder than has been previously assumed. It is important that claims of clinically significant distress be grounded in comparisons to normative data, and that they be backed by evidence that such distress actually reflects impairment or psychiatric morbidity. Thus, a recent paper examined persons who are members of families with known mutations of BRCA1 or BRCA2, but who themselves declined testing (Lerman et al., 1998). Concern was expressed that 18% had elevated distress. Yet this is lower than a primary medical care sample, and even than the baseline assessment of the women in the present sample. Moreover, preliminary findings concerning psychological consequences of genetic testing for risk of breast cancer suggest that there are little enduring effects on levels of psychological distress (Croyle, Smith, Botkin, Baty, & Nash, 1997; Lerman et al., 1996). These results are at variance with what might have been predicted from case reports of the offering of testing to high-risk families (Biesecker et al., 1993; Dudokde-Wit et al., 1997; Lynch et al., 1997), but they are consistent with other empirical findings concerning HD (Codori, Slavney, Young, Miglioretti, & Brandt, 1997; Tibben, Roos, & Niermeijer, 1997; Wiggins et al., 1992).

It is premature to come to any final conclusions concerning the adjustment of high-risk women anticipating and receiving genetic testing for risk of breast and ovarian cancer. However, it is also important that emerging data not be dismissed or distorted simply because they contradict preconceived notions. Unfortunately, that has sometimes been the case in the literature concerning genetic testing. In genetic screening for both Huntington's Disease and mutations of BRCA1, findings that recipients of positive test results do not experience substantial distress have been minimized and distorted (Lawson et al., 1997; Taylor & Myers, 1997) and even dismissed with arguments "that low scores on 'mental health scales' can reflect opposite conditions. Low scores usually indicate good psychological health; on the other hand, distress may be present, but denied in order to

maintain an illusion of mental health." (DukokdeWit et al., 1997, p 387; See also DukokdeWit et al., 1998). Results obtained in larger scale studies of high-risk persons with standardized self-report and semi-structured diagnostic interviews are to be preferred to results of studies using unvalidated measures, and to clinical speculations concerning potentially unrepresentative cases. For instance, the genetic testing literature continues to contain considerable speculation about the risk of "survivor's guilt" among persons who are not found to have gene mutations associated with heightened risk of disease (DukokdeWit et al., 1998; Huggins et al., 1992; Tibben et al., 1997). This is despite no empirical study ever having yielded evidence that being informed that one does not have a mutation increases distress. Finally, interpretation of empirical data should be informed by relevant norms for measures, known correlates, and base rates of phenomena in relevant populations. In the present study, high-risk women were found to be relatively free of psychological distress, and elevated psychological distress was associated with a rate of syndromal depressive and anxiety disorders less than the prevalence of these disorders in unscreened general medical populations. This latter finding suggests the need to temper claims about anxiety and depression associated with testing which are made solely on the basis of self-report measures. Moderately elevated distress scores may simply reflect the norms for relevant comparison populations—a possibility needing more attention in studies lacking a comparison group--and endorsement of items indicating worries about disease may indicate understandable concern about their risk status, rather than psychiatric symptoms, morbidity, or impairment.

High-risk women recruited to a hereditary breast and ovarian registry for the purposes of research undoubtedly represent a socially advantaged group, and demographic information from the sample bore this out. Additional data from this sample has given further indication of the social resources of this group of women (Coyne & Anderson, 1999). The married women had stable and highly satisfying marriages, and their husbands were supportive and involved in decision-making about managing the women's risk status,

including genetic testing. Unmarried women in the sample had similarly low levels of distress, and both married and unmarried women had mobilized considerable support from female relatives. These findings give rise to an important caveat about generalizations from women seeking genetic testing in the context of hereditary cancer registries and research protocols to the larger pool of high-risk women in the community. It is possible that women who seek genetic testing in non-community medical settings outside of research protocols may differ. Some women may seek genetic testing in the community because they are distressed by a recent medical finding such as an ambiguous lump in the breast or an abnormal pap smear, or by a recent death or diagnosis of cancer in a relative. There is evidence that many women with family histories of cancer have not had extensive discussion of the personal implications of this history (Stefanek & Wilcox, 1991). Such women may be particularly ill-prepared for education and decision-making concerning genetic testing. Studies of such women seeking testing under those circumstances are sorely needed.

Requiring that high-risk women seeking predictive testing for risk of breast and ovarian cancer undergo psychological assessment and counseling increases the cost of genetic testing and needs to be justified by data. Moreover, there have recently been null findings concerning the effects of a program offering monthly monitoring of psychological distress and psychosocial intervention for distressed women who have received a diagnosis of breast cancer (Maunsell, Brisson, Deschenes, & Frasure-Smith, 1996). A similar program resulted in negative outcomes for women recovering from myocardial infarction, and the authors suggested that repeated focusing on their relatively minor psychological distress may have disrupted these women's normal coping efforts (Frasure-Smith et al., 1997). These findings are relevant in suggesting that services offered to manage the distress of high-risk women seeking predictive testing for breast cancer must be tailored to their actual, rather than presumed, needs. One possibility raised by the present study is that if high-risk women are no more distressed than women in relevant comparison

populations, than it may not be reasonable to assume that interventions targeting distress will bring about a significant reduction in distress.

One aim of the present study was to establish baseline differences in the adjustment of high-risk women who had histories of cancer versus those who did not. The goal was to provide a means of understanding any changes in the subsequent adjustment of women without histories of cancer who test positive. However, it was instead found that the women with histories of cancer were similarly low in distress and psychiatric disorder, and that there were no differences between women with and without this history. Indeed, we have produced evidence of positive psychological outcomes for long-term survivors of breast cancer with what is perhaps one of the largest samples to receive assessment by psychiatric interview. These results are consistent with past speculations concerning the ability of patients to make a positive long-term adjustment to cancer when they are neither receiving active treatment or facing the terminal stages of the disease (Massie & Holland, 1990).

Overall, we set out in the larger project from which these data were drawn to examine what was presumed to be the psychological vulnerability of women anticipating genetic testing. What we have ended up demonstrating is the remarkable psychological intactness of these women. Attention can be profitably turned to better understanding why these women defy the not unreasonable assumption that they would be a distressed, depressed, and anxious group. The experience of living with familial risk of cancer may well have organized psychological resources and fostered resiliency that more than compensates for any vulnerability associated with it. Adversity can produce resiliency as well as vulnerability (Schaeffer & Moos, 1992; Caspi & Moffitt, 1991), and high-risk women anticipating testing may provide an excellent opportunity to study this.

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Table 1

Basic Demographic Characteristics of the Full Sample, and Women With and Without a
History of Cancer

	<u>All Women</u> N = 464	<u>With a History of Cancer</u> n = 211	<u>Without a History of Cancer</u> n = 253
Age	49.0 (12.2)	51.9 (11.0)	46.2(13.3)
Religion	74%	70%	79%
Christian			
Marital Status			
Married/With	83%	84%	83%
Partner			
Number of	2.0 (1.8)	2.0 (2.0)	2.0 (1.7)
Children			
Education			
At Least Some	80%	76%	81%
College			
Employed Outside	61%	57%	63%
Home	\$54,500	\$54,000	\$54,500
Income			

Table 2

Psychological Distress As Measured by The Hopkins-25

	<u>All Women</u> N = 464	<u>With a History of Cancer</u> n = 211	<u>Without a History of Cancer</u> n = 253
Mean Hopkins-25	37.5 (S.D.=9.2)	37.7 (9.2)	37.5 (9.2)
% in Clinical Range (Greater Than 43)	23%	22%	24%

Table 3
Psychiatric Morbidity As Assessed by Semi-Structured Interview

	<u>All Women</u>	<u>With a</u> <u>History of Cancer</u>	<u>Without a</u> <u>History of Cancer</u>
	N = 464	n = 211	n = 253
<hr/>			
Current Major			
Depression	5 (1%)	4 (2%)	1 (.4%)
Lifetime Major			
Depression	87 (17%)	46 (20%)	41 (15%)
Current Major			
Depression (GMC)	2 (.4%)	2 (.4%)	0
Lifetime Major			
Depression (GMC)	10 (2%)	7 (3%)	3 (1%)
Generalized Anxiety			
Disorder	3 (.6%)	1 (.4%)	2 (.7%)
Mixed Anxiety			
Depression	3 (.6%)	0	3 (1%)
Dysthymia	2 (.4%)	1 (.4%)	1 (.4%)
Alcohol Use Current	1 (.2%)	0	1(.4%)

APPENDIX B

Copies of Measures Used in the Current Study

Proband Baseline Questionnaire (Affected and Unaffected Versions)
Proband Baseline Telephone Interview
Proband Interim Questionnaire
Proband Pre-Results Questionnaire (Affected and Unaffected Versions)
Proband 2-Month Post-Results Interview
Proband 6-Month Post-Results Interview
Proband 6-Month Post-Results Questionnaire
Proband 12-Month Post-Results Questionnaire
Spouse Baseline Questionnaire
Spouse 8-Month Post-Results Questionnaire
Sibling Questionnaire
Long-Term Follow-Up Questionnaire (Male and Female Versions)



WOMEN'S HEALTH STUDY

Baseline Questionnaire

Today's Date _____

ID _____

Background Data

A1. Date of Birth _____ Month _____ Day _____ Year _____

A2. Ethnic Background:

White	<input type="checkbox"/>	Black	<input type="checkbox"/>
Hispanic	<input type="checkbox"/>	Asian	<input type="checkbox"/>
Native American	<input type="checkbox"/>	Other	<input type="checkbox"/>

A3. Religion:

Catholic	<input type="checkbox"/>	Protestant	<input type="checkbox"/>
Jewish	<input type="checkbox"/>	Other	<input type="checkbox"/>
None	<input type="checkbox"/>		

A4. Are you currently (**please check one**)?

- ☐ Single
- ☐ Married
- ☐ Not married, but living in a steady, marriage-like relationship
- ☐ Separated
- ☐ Divorced
- ☐ Widowed

A5a. If you **are** currently married, what was the date of your current marriage?

Month _____ Year _____

A5b. Is this your first marriage? Yes ☐ No ☐

A6. How many children do you have? _____

A6a. Number of children living at home _____

A6b. Number who are under age 6 _____

A7. Are you currently working for pay outside the home?

Yes ☐ No ☐

A8. If **yes**, about how many hours per week are you working for pay?

Less than 10 10-20 21-30 31-40 41 or more

☐ ☐ ☐ ☐ ☐
 A9. What is the highest level of education you have completed? (**Check one**)

- ☐ Less than 9th grade
- ☐ Dropped out of high school
- ☐ Completed high school
- ☐ Some college
- ☐ Completed college
- ☐ Some graduate or professional training
- ☐ Completed graduate or professional training

The following two questions are optional, but we hope that you will provide this information.
 Please check the appropriate box.

A10. What is your household's total income? (**Check one**)

- ☐ Less than \$10,000
- ☐ \$10,000 to \$19,999
- ☐ \$20,000 to \$29,999
- ☐ \$30,000 to \$39,999
- ☐ \$40,000 to \$49,999
- ☐ \$50,000 to \$59,999
- ☐ \$60,000 to \$69,999
- ☐ Greater than \$69,999

A11. How many people (adults and children) does this income support? _____

SECTION B

B1. Have you ever been diagnosed with breast cancer? Yes ☐ No ☐

B2. Have you ever been diagnosed with ovarian cancer? Yes ☐ No ☐

B3. Have you ever had any of the following surgical procedures? (**Please check all that apply**).

- | | |
|---|---|
| _____ Lumpectomy (Removal of lump
from breast) | _____ Oophorectomy (Removal of ovaries) |
| _____ Unilateral mastectomy (Removal
of one breast) | _____ Hysterectomy (Removal of uterus) |
| _____ Bilateral mastectomy (Removal of
both breasts) | |

B4. Compared to the average woman, how Much Less Much More

likely are you to develop breast cancer?

Likely
1 2 3 4 Likely
5

B5. Compared to other women in your family,
how likely are you to develop breast cancer?

Much Less
Likely
1 2 3 4 Much More
Likely
5

B6. Overall, what do you believe your risk to be of developing breast cancer **in the near future?**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B7. Overall, what do you believe your risk to be of developing breast cancer **at some point in your lifetime?**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B8. A medical test may soon be available that allows some individual women to learn their risk for developing a form of breast and ovarian cancer that runs in families. Knowing this, what is your intention concerning this test at the present time? **(Please check one response).**

_____ I will definitely take the test immediately when it becomes available.

_____ I will definitely take the test, but I am not sure if immediately.

_____ I will probably take the test immediately when it becomes available.

_____ I will probably take the test, but not immediately.

_____ I am undecided whether I will take the test.

_____ I will probably not take the test.

_____ I will definitely not take the test.

B9. If you think you will probably or definitely take the test, what are your reasons for doing so? **(Please check all that apply).**

_____ To plan for the future.

_____ To reduce the uncertainty.

_____ To know I have to be more careful about doing breast self examinations and getting regular checkups.

_____ To make decisions about whether to get preventive surgery.

_____ To make decisions about family planning.

_____ To find out the risk that may be transmitted to my children.

_____ Family members want me to get testing.

_____ Other (describe) _____

B10. If you **do not** think you will probably or definitely take the test, what are your reasons for **not** doing so? (Please check all that apply).

- _____ I am happier not knowing.
- _____ It would be too upsetting to learn that I am at high risk for breast cancer.
- _____ I believe I already know what my risk for breast cancer is.
- _____ There would not be much I could do if I found out I was at high risk for breast cancer.
- _____ I do not feel able emotionally to deal with testing.
- _____ Family members do not want me to get testing.
- _____ Risk to my insurance coverage.

B11. If you were to take the test and find out that you **were not** at high risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
a.	I would feel wonderful.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would feel relieved.	1	2	3	4	5
d.	I would not believe the results.	1	2	3	4	5
e.	I would fall apart emotionally.	1	2	3	4	5
f.	I would feel guilty.	1	2	3	4	5
g.	I would still feel anxious.	1	2	3	4	5
h.	I would feel angry.	1	2	3	4	5
i.	I would feel prepared for the future.	1	2	3	4	5
j.	I would feel I had done all I needed to do.	1	2	3	4	5

B12. If you were to take the test and find out that you **were** at high risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
a.	I would feel relieved about being more certain.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would not believe the results.	1	2	3	4	5

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
d.	I would feel guilty.	1	2	3	4	5
e.	I would be depressed.	1	2	3	4	5
f.	I would feel worried about the future.	1	2	3	4	5
g.	I would just fall apart emotionally.	1	2	3	4	5
h.	I would feel anxious.	1	2	3	4	5
i.	I would feel angry.	1	2	3	4	5

B13. To what extent do you agree with the following statements?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
a.	Mammography is effective in the early detection of breast cancer.	1	2	3	4	5
b.	Breast cancer that is detected early is curable.	1	2	3	4	5
c.	Mammography can detect lumps that cannot be felt by you or your doctor.	1	2	3	4	5
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5
e.	My health is too good to consider thinking that I might get breast cancer.	1	2	3	4	5
f.	If a lump is found in your breast, it is usually too late to do anything about it.	1	2	3	4	5
g.	Whenever I hear of a friend/relative or public figure getting breast cancer I realize that I could get it too.	1	2	3	4	5
h.	If I examine my own breasts regularly, I might find a lump sooner than if I wait to go for screening.	1	2	3	4	5
i.	There are so many things that could happen to me that it is pointless to think about breast cancer.	1	2	3	4	5
j.	Even though it is a good idea, I find examination of my breasts an embarrassment.	1	2	3	4	5
k.	The older I get, the more I think about the possibility of getting breast cancer.	1	2	3	4	5
l.	Going for screening has increased my worry about breast cancer.	1	2	3	4	5
m.	If I was found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5

		<i>Not At All</i>			<i>All The Time</i>	
B15.	How often do you worry about developing breast cancer?	1	2	3	4	5
B16.	To what extent do any worries you have about breast cancer interfere with every day life?	1	2	3	4	5

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the **first column**, please keep in mind the female family member at similar risk for breast cancer **with whom you are closest**. Answer the questions in the **second column** keeping in mind **your spouse or intimate partner**. *If you do not have a spouse or intimate partner, please leave the second column blank.* For the **third column**, please keep in mind **another family member or friend to whom you are closest**.

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C1. Was physically present when you needed them.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C2. Told you what he/she did in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C3. Did activities to help you get your mind off things.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C4. Told you that the things you talk about are private--just between the two of you.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C5. Suggested some action you should take.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C6. Comforted you by showing you physical affection.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C7. Listened to you talk about your private feelings.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C8. Agreed that what you want to do is right.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C9. Told you how he/she felt in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C10. Let you know that he/she will always be around if you need assistance.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

	<u>Female Family Member at Risk for Breast Cancer</u>	<u>Spouse/Partner</u>	<u>Another Family Member/ Friend</u>
C11. Gave you feedback on how you were doing without saying it was good or bad.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C12. Pitched in and helped you do things that needed to get done.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C13. Intruded into your personal feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C14. Gave you unsolicited advice.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C15. Attempted to make unwanted contact.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C16. Discouraged you from discussing your feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C17. Minimized your worries or concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C18. Rejected you for displaying emotional upset.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C19. Insisted that you remain upbeat and optimistic.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C20. Let you down when you were counting on him/her.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

C21. Is there anyone in your life with whom you can share your most private feelings without holding back?
☐ yes ☐ no

C21a. **If you are married or living with a partner**, can you share your most private feelings with this partner without holding back?
☐ yes ☐ no

D1. Have any of the events listed happened to you in the past six months? **(Check All That Apply)**

- | | |
|---|--|
| a. <input type="checkbox"/> You retired or were fired or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> You were seriously ill or injured. |

For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. Try to be as accurate and as honest as you can, and try not to let your answer to one question influence your answers to other questions. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>		<i>Neutral</i>		<i>Strongly Agree</i>	
E1.	In uncertain times, I usually expect the best.	1	2	3	4	5	
E2.	It's easy for me to relax.	1	2	3	4	5	
E3.	If something can go wrong for me, it will.	1	2	3	4	5	
E4.	I always look on the bright side of things.	1	2	3	4	5	
E5.	I'm always optimistic about my future.	1	2	3	4	5	
E6.	I enjoy my friends a lot.	1	2	3	4	5	
E7.	It's important for me to keep busy.	1	2	3	4	5	
E8.	I hardly ever expect things to go my way.	1	2	3	4	5	
E9.	Things never work out the way I want them to	1	2	3	4	5	
E10.	I don't get upset too easily.	1	2	3	4	5	
E11.	I'm a believer in the idea that "every cloud has a silver lining".	1	2	3	4	5	
E12.	I rarely count on good things happening to me.	1	2	3	4	5	

Below is a list of words which people might use to describe themselves. You are asked to rate them **twice**. First, please indicate for each word how well it describes you and second, how much it matters to you using the following scale.

1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

		<u>DESCRIBES ME</u>					<u>MATTERS TO ME</u>				
		1	2	3	4	5	1	2	3	4	5
F1.	Involved in family	1	2	3	4	5	1	2	3	4	5
F2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
F3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
F4.	Being a mother	1	2	3	4	5	1	2	3	4	5
F5.	Involved in organization/ volunteer work	1	2	3	4	5	1	2	3	4	5
F6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
F7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
F8.	Being a wife	1	2	3	4	5	1	2	3	4	5
F9.	Healthy	1	2	3	4	5	1	2	3	4	5
F10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
F11.	Intelligent	1	2	3	4	5	1	2	3	4	5
F12.	Able to cope	1	2	3	4	5	1	2	3	4	5
F13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
F14.	Outgoing	1	2	3	4	5	1	2	3	4	5
F15.	Independent	1	2	3	4	5	1	2	3	4	5
F16.	Realistic	1	2	3	4	5	1	2	3	4	5
F17.	Active	1	2	3	4	5	1	2	3	4	5
F18.	Loved	1	2	3	4	5	1	2	3	4	5
F19.	Caring	1	2	3	4	5	1	2	3	4	5
F20.	Depressed	1	2	3	4	5	1	2	3	4	5

In the next table, we would like you to first rate how well you think each word will describe you *in the future*, and then, indicate how important it is for you to see yourself this way *in the future*.

1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

		<u>WILL DESCRIBE YOU</u>					<u>IMPORTANT FOR YOU TO SEE YOURSELF THIS WAY IN FUTURE</u>				
		1	2	3	4	5	1	2	3	4	5
G1.	Involved in family	1	2	3	4	5	1	2	3	4	5
G2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
G3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
G4.	Being a mother	1	2	3	4	5	1	2	3	4	5
G5.	Involved in organization/ volunteer work	1	2	3	4	5	1	2	3	4	5
G6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
G7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
G8.	Being a wife	1	2	3	4	5	1	2	3	4	5
G9.	Healthy	1	2	3	4	5	1	2	3	4	5
G10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
G11.	Intelligent	1	2	3	4	5	1	2	3	4	5
G12.	Able to cope	1	2	3	4	5	1	2	3	4	5
G13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
G14.	Outgoing	1	2	3	4	5	1	2	3	4	5
G15.	Independent	1	2	3	4	5	1	2	3	4	5
G16.	Realistic	1	2	3	4	5	1	2	3	4	5
G17.	Active	1	2	3	4	5	1	2	3	4	5
G18.	Loved	1	2	3	4	5	1	2	3	4	5
G19.	Caring	1	2	3	4	5	1	2	3	4	5
G20.	Depressed	1	2	3	4	5	1	2	3	4	5

The following questions apply to persons who are married or living with a partner. Please complete them if you are. If you are not married or living with a partner, please skip to Section I on page 13.

Most persons have disagreements in their relationships. Please indicate, with check marks, on the following list, the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH.**

		Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances						
H2.	Matters of recreation						
H3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						
H6.	Sex relations						
H7.	Conventionality (correct or proper behavior)						
H8.	Philosophy of life						
H9.	Ways of dealing with parents or in-laws						
H10.	Aims, goals, and things believed important						
H11.	Amount of time spent together						
H12.	Making major decisions						
H13.	Household tasks						
H14.	Leisure time interests and activities						
H15.	Career decisions						

		All of the time	Most of the time	More often than most	Occasionally	Rarely	Never
H16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
H17.	How often do you or your mate leave the house after a fight?						
H18.	In general, how often do you think that things between you and your partner are going well?						
H19.	Do you confide in your mate?						
H20.	Do you ever regret that you married (or lived together)?						
H21.	How often do you and your partner quarrel?						
H22.	How often do you and your mate "get on each other's nerves?"						

		Every Day	Almost Every Day	Occasionally	Rarely	Never
H23.	Do you kiss your mate?					

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them
H24.	Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
H25.	Have a stimulating exchange of ideas.						
H26.	Laugh together.						
H27.	Calmly discuss something.						
H28.	Work together on a project.						

These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. **(Check yes or no).**

H29. Being too tired for sex. ☐ Yes ☐ No

H30. Not showing love. ☐ Yes ☐ No

H31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the statement which best describes the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
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H32. Please check one of the following statements which best describes how you feel about the **future** of your relationship.

- _____ I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
- _____ I want very much for my relationship to succeed, and will do all I can to see that it does.
- _____ I want very much for my relationship to succeed, and will do my fair share to see that it does.
- _____ It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.
- _____ It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
- _____ My relationship can never succeed, and there is no more that I can do to keep the relationship going.

SECTION I

I1. In general, would you say your health is:
☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

I2. Compared to one year ago, how would you rate your health in general now?**(Check one)**

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago

☐ Much worse than one year ago

13. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *Please mark the appropriate box to indicate your response.*

		<i>YES, limited a lot.</i>	<i>YES, limited a little.</i>	<i>NO, not limited at all.</i>
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
c.	Lifting or carrying groceries.			
d.	Climbing several flights of stairs.			
e.	Climbing one flight of stairs.			
f.	Bending, kneeling, or stooping.			
g.	Walking more than a mile.			
h.	Walking several blocks.			
i.	Walking one block.			
j.	Bathing or dressing yourself.			

14. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **physical** health?

a. Cut down the amount of time you spent on work or other activities.

☐ Yes ☐ No

b. Accomplished less than you would like.

☐ Yes ☐ No

c. Were limited in the kind of work or other activities.

☐ Yes ☐ No

d. Had difficulty performing the work or other activities (for example, it took extra effort).

☐ Yes ☐ No

15. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **emotional** problems (such as feeling depressed or anxious)?

- a. Cut down the amount of time you spent on work ☐ Yes ☐ No
or other activities.
- b. Accomplished less than you would like. ☐ Yes ☐ No
- c. Didn't do work or other activities as ☐ Yes ☐ No
carefully as usual.

16. **During the past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- ☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

17. How much bodily pain have you had **during the past 4 weeks**?

- ☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

18. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

19. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks**: *Please mark the appropriate box to indicate your response.*

		<i>All of the time</i>	<i>Most of the time</i>	<i>A good bit of the time</i>	<i>Some of the time</i>	<i>A little of the time</i>	<i>None of the time</i>
a.	Did you feel full of pep?						
b.	Have you been a very nervous person?						
c.	Have you felt so down in the dumps that nothing could cheer you up?						
d.	Have you felt calm and peaceful?						
e.	Did you have a lot of energy?						
f.	Have you felt downhearted and blue?						

		<i>All of the time</i>	<i>Most of the time</i>	<i>A good bit of the time</i>	<i>Some of the time</i>	<i>A little of the time</i>	<i>None of the time</i>
g.	Have you been a happy person?						
h.	Did you feel tired?						

I10. **During the past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

☐ All of the time ☐ Most of the time ☐ A good bit of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

I11. How **TRUE** or **FALSE** is each of the following statements for you?

	<i>Definitely True</i>	<i>Mostly True</i>	<i>Don't Know</i>	<i>Mostly False</i>	<i>Definitely False</i>
a. I seem to get sick a little easier than other people.					
b. I am as healthy as anybody I know.					
c. I expect my health to get worse.					
d. My health is excellent.					

I12. **In the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?

☐ **YES** ☐ **NO**

a. If **yes**, there was such a two-week period, did your work or relationships suffer?

☐ yes ☐ no

b. If **yes**, there was such a two-week period, did you get counseling or psychotherapy?

☐ yes ☐ no

c. If there was such a two-week period, did you get medication for this condition?

☐ yes ☐ no

I13. Are you **currently** receiving counseling or psychotherapy or medication for depression or emotional problems?

☐ **YES** ☐ **NO**

- J1. How often do you have a drink containing alcohol?
☐ Never ☐ Monthly or less ☐ Two to four times a month
☐ Two to three times a week ☐ Four or more times a week
- J2. How many drinks containing alcohol do you have on a typical day when you are drinking?
☐ 1 or 2 ☐ 3 or 4 ☐ 5 or 6 ☐ 7 to 9 ☐ 10 or more
- J3. Have you ever felt you should cut down on your drinking?
☐ YES ☐ NO
- J4. Have people annoyed you by criticizing your drinking?
☐ YES ☐ NO
- J5. Have you ever felt bad or guilty about drinking?
☐ YES ☐ NO
- J6. Have you ever taken a drink first thing in the morning to steady your nerves or get rid of a hangover?
☐ YES ☐ NO
- L1. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check **all** of the statements that might apply to you.
- ☐ I would ask the dentist exactly what he was going to do.
- ☐ I would take a tranquilizer or have a drink before going.
- ☐ I would try to think about pleasant memories.
- ☐ I would want the dentist to tell me when I would feel pain.
- ☐ I would try to sleep.
- ☐ I would watch all the dentist's movements and listen for the sound of the drill.
- ☐ I would watch the flow of water from my mouth to see if it contained blood.
- ☐ I would do mental puzzles in my mind.
- L2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check **all** of the statements that might apply to you.
- ☐ I would sit by myself and have as many daydreams and fantasies as I could.
- ☐ I would stay alert and try to keep myself from falling asleep.
- ☐ I would exchange life stories with the other hostages.
- ☐ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.
- ☐ I would watch every movement of my captors and keep an eye on their weapons.
- ☐ I would try to sleep as much as possible.
- ☐ I would think about how nice it's going to be when I get home.
- ☐ I would make sure I knew where every possible exit was.

L3. Vividly imagine that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off's has been made and will be announced in several days. Check all of the statements that might apply to you.

- ☐ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.
- ☐ I would review the list of duties for my present job and try to figure out if I had fulfilled them all.
- ☐ I would go to the movies to take my mind off things.
- ☐ I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.
- ☐ I would push all thoughts of being laid off out of my mind.
- ☐ I would tell my spouse that I'd rather not discuss my chances of being laid off.
- ☐ I would try to think which employees in my department the supervisor might have thought had done the worst job.
- ☐ I would continue doing my work as if nothing special was happening.

L4. Vividly imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Check all of the statements that might apply to you.

- ☐ I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.
- ☐ I would make small talk with the passenger beside me.
- ☐ I would watch the end of the movie, even if I had seen it before.
- ☐ I would call for the stewardess and ask her exactly what the problem was.
- ☐ I would order a drink or tranquilizer from the stewardess.
- ☐ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.
- ☐ I would talk to the passenger beside me about what might be wrong.
- ☐ I would settle down and read a book or magazine or write a letter.

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

	<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>
K1. Suddenly scared for no reason				
K2. Feeling fearful				
K3. Faintness, dizziness, or weakness				
K4. Nervousness or shakiness inside				
K5. Heart pounding or racing				
K6. Trembling				
K7. Feeling tense or keyed up				
K8. Headaches				
K9. Spells of terror or panic				
K10. Feeling restless, can't sit still				
K11. Feeling low in energy--slowed down				
K12. Blaming yourself for things				
K13. Crying easily				
K14. Loss of sexual interest or pleasure				
K15. Poor appetite				
K16. Difficult falling asleep, staying asleep				
K17. Feeling hopeless about the future				
K18. Feeling blue				
K19. Feeling lonely				
K20. Feeling trapped or caught				
K21. Worrying too much about things				
K22. Feeling no interest in things				
K23. Thoughts of ending your life				
K24. Feeling everything is an effort				
K25. Feelings of worthlessness				

L1. Please indicate how much you agree with the following statements.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
		1	2	3	4	5
a.	If you don't have your health, you don't have anything.	1	2	3	4	5
b.	There are many things I care about more than my health.	1	2	3	4	5
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5
d.	There is nothing more important than good health.	1	2	3	4	5

Please indicate the extent to which each of the following items describes your current family.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
		1	2	3	4	5
M1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
M2.	In times of crisis we can turn to each other for support.	1	2	3	4	5
M3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5
M4.	Individuals are accepted for what they are.	1	2	3	4	5
M5.	We avoid discussing our fears and concerns.	1	2	3	4	5
M6.	We can express feelings to each other.	1	2	3	4	5
M7.	There are lots of bad feelings in the family.	1	2	3	4	5
M8.	We feel accepted for what we are.	1	2	3	4	5
M9.	Making decisions is a problem for our family.	1	2	3	4	5
M10.	We are able to make decisions about how to solve problems.	1	2	3	4	5
M11.	We don't get along well together.	1	2	3	4	5
M12.	We confide in each other.	1	2	3	4	5

THANK YOU VERY MUCH.

				-	
--	--	--	--	---	--

WOMEN'S HEALTH STUDY

Baseline Questionnaire

Today's Date _____

ID-A _____

Background Data

A1. Date of Birth _____Month _____Day _____Year

A2. Ethnic Background: White ☐ Black ☐
 Hispanic ☐ Asian ☐
 Native American ☐ Other ☐

A3. Religion: Catholic ☐ Protestant ☐
 Jewish ☐ Other ☐
 None ☐

A4. Are you currently (please check one)?

☐ Single ☐ Married
☐ Not married, but living in a steady, ☐ Separated
 marriage-like relationship ☐ Divorced ☐ Widowed

A5a. If you **are** currently married, what was the date of your current marriage?
 Month _____ Year _____

A5b. Is this your first marriage? Yes ☐ No ☐

A6. How many children do you have? _____

A6a1. Ages of **DAUGHTERS**: a. _____ b. _____ c. _____
 d. _____ e. _____ f. _____

A6a2. Ages of **SONS**: a. _____ b. _____ c. _____
 d. _____ e. _____ f. _____

A6a. Number of children living at home _____

A6b. Number who are under age 6 _____

A7. Are you currently working for pay outside the home? Yes ☐ No ☐

A8. If **yes**, about how many hours per week are you working for pay?
 Less than 10 10-20 21-30 31-40 41 or more
 ☐ ☐ ☐ ☐ ☐

A9. What is the highest level of education you have completed? (Check one)

☐ Less than 9th grade ☐ Dropped out of high school
☐ Completed high school ☐ Some college
☐ Completed college ☐ Some graduate or professional
☐ Completed graduate or professional training training

The following two questions are optional, but we hope that you will provide this information.
Please check the appropriate box. (Check one)

A10. What is your household's total income? (Check one)

- | | | |
|---|--|---|
| <input type="checkbox"/> Less than \$10,000 | <input type="checkbox"/> \$10,000 to \$19,999 | <input type="checkbox"/> \$20,000 to \$29,999 |
| <input type="checkbox"/> \$30,000 to \$39,999 | <input type="checkbox"/> \$40,000 to \$49,999 | <input type="checkbox"/> \$50,000 to \$59,999 |
| <input type="checkbox"/> \$60,000 to \$69,999 | <input type="checkbox"/> Greater than \$69,999 | |

A11. How many people (adults and children) does this income support? _____

B1. When were you first diagnosed with breast cancer? Month _____ Year _____

B2. Have your lymph nodes been affected?
Yes ☐ No ☐ Do Not Know ☐

B3. Do you currently consider yourself in remission?
Yes ☐ No ☐ Do Not Know ☐

B4. What treatment(s) have you received for breast cancer?
Chemotherapy Yes ☐ No ☐
Radiation Yes ☐ No ☐
Surgery Yes ☐ No ☐

B5. Have you ever been diagnosed with ovarian cancer? Yes ☐ No ☐
If yes, when? Month _____ Year _____

B6. Have you ever had any of the following surgical procedures? (Please check all that apply).

B6a. _____ Lumpectomy (Removal of lump from breast)
If yes, when? Month _____ Year _____

B6b. _____ Oophorectomy (Removal of ovaries)
If yes, when? Month _____ Year _____

B6c. _____ Unilateral mastectomy (Removal of one breast)
If yes, when? Month _____ Year _____

B6d. _____ Hysterectomy (Removal of uterus)
If yes, when? Month _____ Year _____

B6e. _____ Bilateral mastectomy (Removal of both breasts)
If yes, when? Month _____ Year _____

B7. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to the average woman? (Please circle one)
Much Less Likely Much More Likely
1 2 3 4 5

B8. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women in your family? (Please circle one)
Much Less Likely Much More Likely
1 2 3 4 5

B9. Overall, what do you believe your risk is of developing breast cancer *again* in the near future?
0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B10. Overall, what do you believe your risk is of developing breast cancer *again* at some point in your lifetime?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B11. Overall, what do you believe your risk is of developing a metasis (cancer spreading to another site) in the near future?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B12. Overall, what do you believe your risk is of developing a metasis at some point in your lifetime?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90%

B13. Overall, what do you believe your risk is of developing cancer **unrelated** to your breast cancer in the near future?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B14. Overall, what do you believe your risk is of developing cancer **unrelated** to your breast cancer at some point in your lifetime?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B15. A medical test may soon be available that allows some women to learn their genetic risk for developing a form of breast and ovarian cancer that runs in families. Even though you have been diagnosed with breast cancer, would you consider taking the genetic test to learn if your cancer is the type that runs in families? **(Please check one response).**

_____ I will definitely take the test immediately when it becomes available.

_____ I will definitely take the test, but I am not sure if immediately.

_____ I will probably take the test immediately when it becomes available.

_____ I will probably take the test, but not immediately.

_____ I am undecided whether I will take the test.

_____ I will probably not take the test.

_____ I will definitely not take the test.

B16. If you think you will probably or definitely take the test, what are your reasons for doing so? **(Please check all that apply; some may not apply to you).**

_____ To plan for the future.

_____ To reduce the uncertainty.

_____ To know I have to be more careful about doing self examinations and getting regular checkups.

_____ To make decisions about whether to get preventive surgery.

_____ To make decisions about family planning.

_____ To find out the risk that may be transmitted to my children.

_____ Family members want me to get testing.

_____ Other (describe) _____

B17. If you **do not** think you will probably or definitely take the test, what are your reasons for **not** doing so? **(Please check all that apply; some may not apply to you).**

_____ I am happier not knowing.

_____ It would be too upsetting to learn that I am at high risk for breast cancer.

_____ I believe I already know what my risk for breast cancer is.

_____ There would not be much I could do if I found out I was at high risk for breast cancer.

_____ I do not feel able emotionally to deal with testing.

_____ Family members do not want me to get testing.

_____ Risk to my insurance coverage.

SECTION C

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the **first column**, please keep in mind a female family member who may be at risk for breast cancer **with whom you are closest**. Answer the questions in the **second column** keeping in mind **your spouse or intimate partner**. *If you do not have a spouse or intimate partner, please leave the second column blank.* For the **third column**, please keep in mind **another family member or friend to whom you are closest**.

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C1. Was physically present when you needed them.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C2. Told you what he/she did in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C3. Did activities to help you get your mind off things.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C4. Told you that the things you talk about are private--just between the two of you.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C5. Suggested some action you should take.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C6. Comforted you by showing you physical affection.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C7. Listened to you talk about your private feelings.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C8. Agreed that what you want to do is right.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C9. Told you how he/she felt in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C10. Let you know that he/she will always be around if you need assistance.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C11. Gave you feedback on how you were doing without saying it was good or bad.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C12. Pitched in and helped you do things that needed to get done.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

C13. Intruded into your personal feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C14. Gave you unsolicited advice.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C15. Attempted to make unwanted contact.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C16. Discouraged you from discussing your feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C17. Minimized your worries or concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C18. Rejected you for displaying emotional upset.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C19. Insisted that you remain upbeat and optimistic.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C20. Let you down when you were counting on him/her.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

C21. Is there anyone in your life with whom you can share your most private feelings without holding back?
☐ Yes ☐ No

C21a. If you are married or living with a partner, can you share your most private feelings with this partner without holding back?
☐ Yes ☐ No

SECTION D

D1. Have any of the events listed happened to you in the past six months? **(Check All That Apply)**

- | | |
|---|--|
| a. <input type="checkbox"/> You retired or were fired or laid off from work. | d. <input type="checkbox"/> Your spouse was unemployed and looking for work. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | e. <input type="checkbox"/> You had problems with the police or court. |
| c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work. | f. <input type="checkbox"/> You got into serious financial difficulties. |

- g. ☐ A close family member was seriously ill or injured.
- h. ☐ You had a marital separation or divorce.
- i. ☐ You had serious troubles with relatives or close friends.
- j. ☐ Your spouse had troubles difficulties with relatives or close friends.
- k. ☐ A close family member died.
- l. ☐ A close friend or relative died.
- m. ☐ You were seriously ill or injured.

SECTION E

For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. Try to be as accurate and as honest as you can, and try not to let your answer to one question influence your answers to other questions. There are no right or wrong answers. We are only interested in your opinions.

		Strongly Disagree		Neutral		Strongly Agree
E1.	In uncertain times, I usually expect the best.	1	2	3	4	5
E2.	It's easy for me to relax.	1	2	3	4	5
E3.	If something can go wrong for me, it will.	1	2	3	4	5
E4.	I always look on the bright side of things.	1	2	3	4	5
E5.	I'm always optimistic about my future.	1	2	3	4	5
E6.	I enjoy my friends a lot.	1	2	3	4	5
E7.	It's important for me to keep busy.	1	2	3	4	5
E8.	I hardly ever expect things to go my way.	1	2	3	4	5
E9.	Things never work out the way I want them to	1	2	3	4	5
E10.	I don't get upset too easily.	1	2	3	4	5
E11.	I'm a believer in the idea that "every cloud has a silver lining".	1	2	3	4	5
E12.	I rarely count on good things happening to me.	1	2	3	4	5

PLEASE CONTINUE ON TO NEXT PAGE

SECTION F

Below is a list of words which people might use to describe themselves. You are asked to rate them twice. First, please indicate for each word how well it describes you and second, how much it matters to you using the following scale.

1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

		<i>DESCRIBES ME</i>					<i>MATTERS TO ME</i>				
		1	2	3	4	5	1	2	3	4	5
F1.	Involved in family	1	2	3	4	5	1	2	3	4	5
F2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
F3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
F4.	Being a mother	1	2	3	4	5	1	2	3	4	5
F5.	Involved in organization/ volunteer work	1	2	3	4	5	1	2	3	4	5
F6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
F7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
F8.	Being a wife	1	2	3	4	5	1	2	3	4	5
F9.	Healthy	1	2	3	4	5	1	2	3	4	5
F10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
F11.	Intelligent	1	2	3	4	5	1	2	3	4	5
F12.	Able to cope	1	2	3	4	5	1	2	3	4	5
F13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
F14.	Outgoing	1	2	3	4	5	1	2	3	4	5
F15.	Independent	1	2	3	4	5	1	2	3	4	5
F16.	Realistic	1	2	3	4	5	1	2	3	4	5
F17.	Active	1	2	3	4	5	1	2	3	4	5
F18.	Loved	1	2	3	4	5	1	2	3	4	5
F19.	Caring	1	2	3	4	5	1	2	3	4	5
F20.	Depressed	1	2	3	4	5	1	2	3	4	5

SECTION G

In the next table, we would like you to first rate how well you think each word will describe you *in the future*. and then, indicate how important it is for you to see yourself this way *in the future*.

1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

		<u>WILL DESCRIBE YOU</u>					<u>IMPORTANT FOR YOU TO SEE YOURSELF THIS WAY IN FUTURE</u>				
		1	2	3	4	5	1	2	3	4	5
G1.	Involved in family	1	2	3	4	5	1	2	3	4	5
G2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
G3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
G4.	Being a mother	1	2	3	4	5	1	2	3	4	5
G5.	Involved in organization/volunteer work	1	2	3	4	5	1	2	3	4	5
G6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
G7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
G8.	Being a wife	1	2	3	4	5	1	2	3	4	5
G9.	Healthy	1	2	3	4	5	1	2	3	4	5
G10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
G11.	Intelligent	1	2	3	4	5	1	2	3	4	5
G12.	Able to cope	1	2	3	4	5	1	2	3	4	5
G13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
G14.	Outgoing	1	2	3	4	5	1	2	3	4	5
G15.	Independent	1	2	3	4	5	1	2	3	4	5
G16.	Realistic	1	2	3	4	5	1	2	3	4	5
G17.	Active	1	2	3	4	5	1	2	3	4	5
G18.	Loved	1	2	3	4	5	1	2	3	4	5
G19.	Caring	1	2	3	4	5	1	2	3	4	5
G20.	Depressed	1	2	3	4	5	1	2	3	4	5

SECTION H

The following questions apply to persons who are married or living with a partner. Please complete them if you are. If you are not married or living with a partner, please skip to Section I on page 13.

Most persons have disagreements in their relationships. Please indicate, with check marks, on the following list, the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances						
H2.	Matters of recreation						
H3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						
H6.	Sex relations						
H7.	Conventionality (correct or proper behavior)						
H8.	Philosophy of life						
H9.	Ways of dealing with parents or in-laws						
H10.	Aims, goals, and things believed important						
H11.	Amount of time spent together						
H12.	Making major decisions						
H13.	Household tasks						
H14.	Leisure time interests and activities						
H15.	Career decisions						

		All of the time	Most of the time	More often than most	Occasionally	Rarely	Never
H16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
H17.	How often do you or your mate leave the house after a fight?						
H18.	In general, how often do you think that things between your and your partner are going well?						
H19.	Do you confide in your mate?						
H20.	Do you ever regret that you married (or lived together)?						
H21.	How often do you and your partner quarrel?						
H22.	How often do you and your mate "get on each other's nerves?"						

		Every Day	Almost Every Day	Occasionally	Rarely	Never
H23.	Do you kiss your mate?					

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them
H24.	Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
H25.	Have a stimulating exchange of ideas.						
H26.	Laugh together.						
H27.	Calmly discuss something.						
H28.	Work together on a project.						

These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. (Check yes or no).

H29. Being too tired for sex. ☐ Yes ☐ No

H30. Not showing love. ☐ Yes ☐ No

H31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the statement which best describes the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
----------------------	-------------------	---------------------	-------	---------------	--------------------	---------

H32. Please check one of the following statements which best describes how you feel about the **future** of your relationship.

_____ I want desperately for my relationship to succeed, and would go to almost any length to see that it does.

_____ I want very much for my relationship to succeed, and will do all I can to see that it does.

_____ I want very much for my relationship to succeed, and will do my fair share to see that it does.

_____ It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.

_____ It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

_____ My relationship can never succeed, and there is no more that I can do to keep the relationship going.

PLEASE CONTINUE ON TO NEXT PAGE
SECTION I

11. In general, would you say your health is:

☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

12. Compared to one year ago, how would you rate your health in general now? (Check one)

- ☐ Much better now than one year ago
☐ Somewhat better now than one year ago
☐ About the same as one year ago
☐ Somewhat worse now than one year ago
☐ Much worse than one year ago

13. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *Please mark the appropriate box to indicate your response.*

		YES, limited a lot.	YES, limited a little.	NO, not limited at all.
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
c.	Lifting or carrying groceries.			
d.	Climbing several flights of stairs.			
e.	Climbing one flight of stairs.			
f.	Bending, kneeling, or stooping.			
g.	Walking more than a mile.			
h.	Walking several blocks.			
i.	Walking one block.			
j.	Bathing or dressing yourself.			

4. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **physical** health?

I4a. Cut down the amount of time you spent on work or other activities.

☐ Yes ☐ No

I4b. Accomplished less than you would like.

☐ Yes ☐ No

I4c. Were limited in the kind of work or other activities.

☐ Yes ☐ No

I4d. Had difficulty performing the work or other activities (for example, it took extra effort).

☐ Yes ☐ No

15. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **emotional** problems (such as feeling depressed or anxious)?

I5a. Cut down the amount of time you spent on work or other activities. ☐ Yes ☐ No

I5b. Accomplished less than you would like. ☐ Yes ☐ No

I5c. Didn't do work or other activities as carefully as usual. ☐ Yes ☐ No

16. **During the past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

17. How much bodily pain have you had **during the past 4 weeks**?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

18. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

I9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks**: Please mark the appropriate box to indicate your response.

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a.	Did you feel full of pep?						
b.	Have you been a very nervous person?						
c.	Have you felt so down in the dumps that nothing could cheer you up?						
d.	Have you felt calm and peaceful?						
e.	Did you have a lot of energy?						
f.	Have you felt downhearted and blue?						
g.	Have you been a happy person?						
h.	Did you feel tired?						

I10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ☐ All of the time
 ☐ Most of the time
 ☐ A good bit of the time
 ☐ Some of the time
 ☐ A little of the time
 ☐ None of the time

PLEASE CONTINUE ON TO NEXT PAGE

I11. How **TRUE** or **FALSE** is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people.					
b. I am as healthy as anybody I know.					
c. I expect my health to get worse.					
d. My health is excellent.					

I12. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?

I12a. If **yes**, there was such a two-week period, did your work or relationships suffer?

☐ Yes ☐ No

I12b. If **yes**, there was such a two-week period, did you get counseling or psychotherapy?

☐ Yes ☐ No

I12c. If there was such a two-week period, did you get medication for this condition?

☐ Yes ☐ No

I13. Are you **currently** receiving counseling or psychotherapy or medication for depression or emotional problems?

☐ Yes ☐ No

PLEASE CONTINUE ON TO NEXT PAGE

SECTION J

- J1. How often do you have a drink containing alcohol?
- ☐ Never ☐ Monthly or less ☐ Two to four times a month
☐ Two to three times a week ☐ Four or more times a week
- J2. How many drinks containing alcohol do you have on a typical day when you are drinking?
- ☐ 1 or 2 ☐ 3 or 4 ☐ 5 or 6 ☐ 7 to 9 ☐ 10 or more
- J3. Have you ever felt you should cut down on your drinking?
- ☐ Yes ☐ No
- J4. Have people annoyed you by criticizing your drinking?
- ☐ Yes ☐ No
- J5. Have you ever felt bad or guilty about drinking?
- ☐ Yes ☐ No
- J6. Have you ever taken a drink first thing in the morning to steady your nerves or get rid of a hangover?
- ☐ Yes ☐ No

PLEASE CONTINUE ON TO NEXT PAGE

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months.***

	<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>
K1. Suddenly scared for no reason				
K2. Feeling fearful				
K3. Faintness, dizziness, or weakness				
K4. Nervousness or shakiness inside				
K5. Heart pounding or racing				
K6. Trembling				
K7. Feeling tense or keyed up				
K8. Headaches				
K9. Spells of terror or panic				
K0. Feeling restless, can't sit still				
K11. Feeling low in energy--slowed down				
K12. Blaming yourself for things				
K13. Crying easily				
K14. Loss of sexual interest or pleasure				
K15. Poor appetite				
K16. Difficult falling asleep, staying asleep				
K17. Feeling hopeless about the future				
K18. Feeling blue				
K9. Feeling lonely				
K20. Feeling trapped or caught				
K21. Worrying too much about things				
K22. Feeling no interest in things				
K23. Thoughts of ending your life				
K24. Feeling everything is an effort				
K25. Feelings of worthlessness				

SECTION L

- L1. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check all of the statements that might apply to you.

_____ I would ask the dentist exactly what he was going to do.

_____ I would take a tranquilizer or have a drink before going.

_____ I would try to think about pleasant memories.

_____ I would want the dentist to tell me when I would feel pain.

_____ I would try to sleep.

_____ I would watch all the dentist's movements and listen for the sound of the drill.

_____ I would watch the flow of water from my mouth to see if it contained blood.

_____ I would do mental puzzles in my mind.

- L2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check all of the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could.

_____ I would stay alert and try to keep myself from falling asleep.

_____ I would exchange life stories with the other hostages.

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.

_____ I would watch every movement of my captors and keep an eye on their weapons.

_____ I would try to sleep as much as possible.

_____ I would think about how nice it's going to be when I get home.

_____ I would make sure I knew where every possible exit was.

- L3. Vividly imagine that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off's has been made and will be announced in several days. Check all of the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all.

_____ I would go to the movies to take my mind off things.

_____ I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.

_____ I would push all thoughts of being laid off out of my mind.

_____ I would tell my spouse that I'd rather not discuss my chances of being laid off.

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job.

_____ I would continue doing my work as if nothing special was happening.

- L4. Vividly imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Check all of the statements that might apply to you.

_____ I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.

_____ I would make small talk with the passenger beside me.

_____ I would watch the end of the movie, even if I had seen it before.

_____ I would call for the stewardess and ask her exactly what the problem was.

_____ I would order a drink or tranquilizer from the stewardess.

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.

_____ I would talk to the passenger beside me about what might be wrong.

_____ I would settle down and read a book or magazine or write a letter.

L5. Please indicate how much you agree with the following statements.

		Strongly Disagree			Strongly Agree	
		1	2	3	4	5
a.	If you don't have your health, you don't have anything.	1	2	3	4	5
b.	There are many things I care about more than my health.	1	2	3	4	5
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5
d.	There is nothing more important than good health.	1	2	3	4	5

Please indicate the extent to which each of the following items describes your current family.

		Strongly Disagree			Strongly Agree	
		1	2	3	4	5
M1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
M2.	In times of crisis we can turn to each other for support.	1	2	3	4	5
M3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5
M4.	Individuals are accepted for what they are.	1	2	3	4	5
M5.	We avoid discussing our fears and concerns.	1	2	3	4	5
M6.	We can express feelings to each other.	1	2	3	4	5
M7.	There are lots of bad feelings in the family.	1	2	3	4	5
M8.	We feel accepted for what we are.	1	2	3	4	5
M9.	Making decisions is a problem for our family.	1	2	3	4	5
M10.	We are able to make decisions about how to solve problems.	1	2	3	4	5
M11.	We don't get along well together.	1	2	3	4	5
M12.	We confide in each other.	1	2	3	4	5

THANK YOU VERY MUCH.

As you may already know, there are two components to this breast cancer research--a study of the biology of genetics, which is now located at the University of Pennsylvania (previously it was at the University of Michigan) and a study of the personal and social aspects of genetic testing which is located at the University of Michigan. This questionnaire is part of the study of personal and social aspects. Some of these questions will be familiar. We are asking them again to learn more about how feelings and attitudes change over time.

If you have any questions about this questionnaire or research, please feel free to call me at 313-998-6560. For questions about the genetic testing component, you may call Kathleen Calzone at the University of Pennsylvania, 215-349-8141. Thank you very much for your valuable participation in this research.

Sean Bouvrette
Project Manager
Women's Health Study
University of Michigan



WOMEN'S HEALTH STUDY

Interim Questionnaire

TODAY'S DATE _____

ID _____

INTERIM QUESTIONNAIRE - U

GENETIC TESTING-SECTION 1

1. Have you contributed a blood or tissue sample to the GENETIC TESTING portion of the research project?

☐ Yes ☐ No

B21.

2. Has any member of your family contributed a blood or tissue sample to the GENETIC TESTING portion of the research project?

☐ Yes ☐ No ☐ I Don't Know

B22.

3. Have you or any family members received notification that genetic results are available?

B23.

There Has Been No Notification	Results Are Available	Results Are NOT YET Available	Results will NEVER BE Available, I am Not Eligible

4. Have **you** received results of genetic testing for breast or ovarian cancer?

☐ Yes ☐ No (Skip to Question 5)

4a. When did this occur? _____ (mo/yr)

4b. What was the source of this information?

☐ University of Pennsylvania ☐ Independent Testing ☐ Other: _____

4c. What were the results? (Optional)

5. Has **any family member** received results of genetic testing for breast or ovarian cancer?

☐ Yes ☐ No (Skip to Next Section) ☐ Don't Know (Skip to Next Section)

5a. When did this occur? _____ (mo/yr)

5b. What was the source of this information?

☐ University of Pennsylvania ☐ Independent Testing ☐ Other: _____

5c. What were the results? (Optional)

5d. Can you infer your genetic results from your relative's results (i.e., Have you been able to figure out whether you are positive or negative for the gene that conveys higher risk for breast cancer with this information?)

☐ Yes ☐ No ☐ Don't Know

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

GENETIC TESTING-SECTION 2

1. A medical test may soon be available that allows some women to learn their genetic risk for developing a form of breast and ovarian cancer that runs in families. Would you consider taking this genetic test?

(Please check one response).

B15.

- (1). _____ I will definitely take the test immediately when it becomes available.
 (2). _____ I will definitely take the test, but I am not sure if immediately.
 (3). _____ I will probably take the test immediately when it becomes available.
 (4). _____ I will probably take the test, but not immediately.
 (5). _____ I am undecided whether I will take the test
 (6). _____ I will probably not take the test.
 (7). _____ I will definitely not take the test.

2. On the following scale, indicate how distressing it is for you to know that you may be at increased risk for breast cancer because of your family history?

B66.

Not At All Distressing			Very Distressing	
1	2	3	4	5

3. How distressing it is to be given the opportunity to be tested for the BRCA-1 gene, the altered gene associated with increased risk for breast cancer?

B67.

Not At All Distressing			Very Distressing	
1	2	3	4	5

4. How distressed do you expect to be when you actually get tested for the BRCA-1 gene (before you receive results)?

B68.

Not At All Distressed			Very Distressed	
1	2	3	4	5

5. How distressed would you be if you took the test and found that you **had** the BRCA-1 gene?

B69.

Not At All Distressed			Very Distressed	
1	2	3	4	5

6. How distressed would you be if you took the test and found that you **did not have** the BRCA-1 gene? **B70.**

Not At All Distressed			Very Distressed	
1	2	3	4	5

7. Overall, to what extent do you welcome the opportunity to be tested for the BRCA-1 gene? **B71.**

Not At All			Very Much So	
1	2	3	4	5

		Not At All		All The Time			
8.	How often do you worry about developing breast cancer?	1	2	3	4	5	B27.
9.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
10.	How often do you worry about having the altered gene carrying risk for breast cancer ?	1	2	3	4	5	B29.
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B30.

12. When was the last time you had a mammography? **B32.**

(-8)
 _____Month _____Year ☐ This question does not apply because of surgery.

13. How many times have you conducted a breast self-examinations (BSE) in the past six months? **B33.**

_____times (-8) ☐ This question does not apply because of surgery.

14. How confident are you that you will perform breast self examination (BSE) ---

14a. --as **frequently** as needed? (-8) ☐ Does Not Apply Because of Surgery B34a.

Not at All Very Much So
1 2 3 4 5 6 7

14b. --as **carefully and competently** as needed? B34b.

(-8) ☐ Does Not Apply Because of Surgery

Not at All Very Much So
1 2 3 4 5 6 7

For each of the following areas of your life, you will be asked to make two ratings. First, indicate how much these decisions have been affected by the possibility that you have an increased risk for breast cancer (based on your family history). Second, how much would these decisions be affected by the results of genetic testing ?

1	2	3	4	5
Not at all affected			Very much affected	

		<u>Have been affected by being at</u> <u>risk for breast cancer</u>					<u>Would be affected by the results of</u> <u>genetic testing</u>					
		1	2	3	4	5	1	2	3	4	5	
15.	Decisions about having children											B35a B35b
16.	Decisions about form of birth control											B36a B36b
17.	Decisions about which steps to take to prevent the occurrence of breast cancer											B37a B37b
18.	Decisions about work and career											B38a B38b
19.	Decisions about savings and financial planning											B39a B39b
20.	Decisions about plans for the future											B40a B40b

21. Answer the following question only if you have (biological) daughters.

☐ Does Not Apply
(Skip to Question 22)

B41.

		<u>Have been affected by being at high risk for breast cancer</u>					<u>Would be affected by the results of genetic testing</u>					
a.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42

22. Do you feel you have enough information about breast cancer to make any decisions that might be necessary?

Not At All		Very Much					
1	2	3	4	5	6	7	B43.

23. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer?

Not At All		Very Much					
1	2	3	4	5	6	7	B44.

24. Do you feel you are adequately informed about what you could do to reduce your risk of breast cancer if you had the altered BRCA1 gene?

Not At All		Very Much					
1	2	3	4	5	6	7	B45.

25. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have the altered BRCA1 gene?

Not At All		Very Much					
1	2	3	4	5	6	7	B46.

26. Do you feel you are adequately informed about what it would mean for your children if you had the altered BRCA1 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B47.

27. How confident are you that you:

- a. Will make the best decision in deciding whether to be tested for BRCA1, the altered gene associated with risk of breast cancer?

Not At All				Very Much		
1	2	3	4	5	6	7

B48a.

- b. Would cope effectively with a finding that you had the altered BRCA1 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B48b.

- c. Would make the best decision concerning your options if you were found to have the altered BRCA1 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B48c.

- d. Would be able to follow through and cope effectively over the long haul if you were found to have the altered BRCA1 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B48d.

RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.
(1) ☐ Yes (5) ☐ No
2. If married, can you share your most private feelings with your husband without holding back? C21a.
(1) ☐ Yes (5) ☐ No
3. If married, is there anyone besides your husband with whom you can share your most private feelings without holding back? C21b.
(1) ☐ Yes (5) ☐ No
-

LIFE EVENTS SECTION

1. Have any of the following events happened to you in the past six months? D1(a-m)
(Check All That Apply)
- | | |
|--|---|
| a. <input type="checkbox"/> You retired, were fired, or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired, was fired, or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles or difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> You were seriously ill or injured. |
-

MARRIAGE SECTION

The following questions apply to persons who are married or living with a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

Not married or living with a partner ☐

E-a.

Most persons have disagreements in their relationships. Please check the appropriate box to indicate the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**, regarding.

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occasionally Disagree</i>	<i>Frequently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Religious matters	6	5	4	3	2	1	H3.
2.	Demonstration of affection	6	5	4	3	2	1	H4.
3.	Sex relations	6	5	4	3	2	1	H6.
4.	Conventionality (correct or proper behavior)	6	5	4	3	2	1	H7.
5.	Making major decisions	6	5	4	3	2	1	H12.
6.	Career decisions	6	5	4	3	2	1	H15.

		<i>All of the time</i>	<i>Most of the time</i>	<i>More often than most</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
8.	Do you ever regret that you married (or are living together)?	1	2	3	4	5	6	H20.
9.	How often do you and your husband/partner quarrel?	1	2	3	4	5	6	H21.
10.	How often do you and your husband/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>
--------------------	---------------------	---------------------	-------------------------	---------------------

11.	Do you and your husband/partner engage in outside interests together?	5	4	3	2	1
-----	---	---	---	---	---	---

H24.

How often would you say the following events occur between you and your husband/partner?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

15. Considering **only the positive feelings** you have toward your husband/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

H33.

Not At All Positive					Extremely Positive				
1	2	3	4	5	6	7	8	9	10

16. Considering **only the negative feelings** you have toward your husband/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative					Extremely Negative				
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your husband's involvement in your health care.

		<div style="display: flex; justify-content: space-between; width: 100%;"> <i>Never</i> <i>Very Often</i> </div>					
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	H35b.
c.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	H35c.
d.	How often does your husband/partner change his activities to assist you in your health care?	1	2	3	4	5	H35d.

18. Has your husband/partner attended individual, family or group sessions to become informed about your risk for breast cancer and what can be done? H36.

1
5
 Yes ☐ No ☐

19. How much contact has your husband/partner had with medical personnel concerning your risk for breast cancer. H37.

Very Little or None A lot
 1 2 3 4 5 6 7

20. Do you feel your husband/partner is adequately informed concerning your risk for breast cancer and what can be done about it? H38.

Not at All Very Much
 1 2 3 4 5 6 7

21. To what extent are you satisfied with your husband/partner's involvement in your health care? H39.

Not at All Very Much
 1 2 3 4 5 6 7

MOOD SECTION

1. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14
- 1 5
- ☐ Yes ☐ No (Skip to Question 2)
- 1a. If there was such a two-week period, did your work or relationships suffer? I14a.
- 1 5
- ☐ Yes ☐ No
- 1b. If there was such a two-week period, did you get counseling or psychotherapy? I14b.
- 1 5
- ☐ Yes ☐ No
- 1c. If there was such a two-week period, did you get medication for this condition? I14c.
- 1 5
- ☐ Yes ☐ No
2. In **the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
- 1 5
- ☐ Yes ☐ No (Skip to Question 3)
- 2a. If there was such a two-week period in **the past 6 months**, did your work or relationships suffer? I12a.
- 1 5
- ☐ Yes ☐ No
- 2b. If there was such a two-week period in **the past 6 months**, did you get counseling or psychotherapy? I12b.
- 1 5
- ☐ Yes ☐ No
- 2c. If there was such a two-week period in **the past 6 months**, did you get medication for this condition? I12c.
- 1 5
- ☐ Yes ☐ No
3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems? I13.
- 1 5
- ☐ Yes ☐ No

STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE.
Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the Past Three Months.

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected positively by your risk of breast cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have the gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
n.	I've been giving up the attempt to cope.	1	2	3	4
o.	I've been accepting the possibility that I might have the gene.	1	2	3	4
p.	I've been expressing my negative feelings.	1	2	3	4
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4
s.	I've been thinking hard about what steps to take.	1	2	3	4
t.	I've been praying or meditating.	1	2	3	4
u.	I've been making fun of the situation.	1	2	3	4

L7n.

L7o.

L7p.

L7q.

L7r.

L7s.

L7t.

L7u.

3. The following items are to be answered only by those women who are married or living with a partner.

☐ Not married or living with a partner

L8.

(Skip to Last Section on page 15, Background Data)

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
a.	I've been denying or hiding my anger around my husband/partner.	1	2	3	4
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4

L8a.

L8b.

L8c.

L8d.

BACKGROUND DATA

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1. Religion: Catholic (1) ☐ Protestant (4) ☐ A3.
Jewish (2) ☐ Buddhist (5) ☐
Muslim (3) ☐ Other (6) ☐
None (7) ☐

- 1a. How often do you attend religious services? A3a.
(1) (5)
☐ Less Often Than Once a Month ☐ A Few Times A Month or More

- 1b. How important are religious and spiritual beliefs in your life? A3b.
Not at All 1 2 3 4 Very Important 5

Once Again, We thank you for all of your valued participation in this study.

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Women's Health Study

Telephone Questionnaire

Revised 4/19/96

Introduction/Confidentiality Statement

Hello. My name is _____. I'm calling from the Women's Health Study. Thank you for returning your questionnaire. As we had mentioned, we have some questions about your opinions, experiences, and feelings related to cancer and genetic testing, and about your mood. You may have provided some of this information already, but it is important that we update our records. Before we start, I would like to assure you that your name was picked randomly from the pool of people that had volunteered for the genetic studies. We do not have any new information about your status. I would also like to assure you that this interview is confidential and completely voluntary. If we should come to any questions which you do not want to answer or which do not apply to you, just let me know and we will go on to the next question. For quality control purposes, we would like to tape record this interview if that is all right with you. ...May we begin?

Date_____

Length of IW_____

Length of Edit_____

Interviewer_____

CANCER STATUS:

- 1a. I understand that you (have/have not) been diagnosed with breast cancer.

1. Have Been Diagnosed	5. Have Not
------------------------	-------------

	Breast Cancer Positive
	Ovarian Cancer Positive

IF R INDICATES "HAVE BEEN DIAGNOSED" TO 1a:

- 1b. When were you diagnosed?

DATE: _____ (month/year)

- 1c. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not At All Distressing			Very Distressing	
1	2	3	4	5

- 2a. I understand that you (have/have not) been diagnosed with ovarian cancer.

1. Have Been Diagnosed	5. Have Not
------------------------	-------------

IF R INDICATES "HAVE BEEN DIAGNOSED" TO 2a:

- 2b. When were you diagnosed?

DATE: _____ (month/year)

- 2c. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not At All Distressing			Very Distressing	
1	2	3	4	5

IF R INDICATES "HAVE BEEN DIAGNOSED" TO EITHER 1a OR 2a OR BOTH:

- 2d. Have you ever had a second diagnosis of cancer? E.G. AFTER REMISSION, ETC.

1. Yes	5. No
--------	-------

IF R INDICATES "YES" TO 2d:

2e. When did you receive this second diagnosis?

DATE: _____ (month/year)

2f. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not At All Distressing			Very Distressing	
1	2	3	4	5

IF R INDICATES "YES" or "HAVE BEEN DIAGNOSED" TO 1a, 2a, OR 2d:

2g. Is your cancer currently in remission?

1. Yes	5. No
--------	-------

IF R INDICATES "YES" TO 2g:

2h. How long has your cancer been in remission?

TIME: _____ (months)

2i. On a scale from 1 to 5, how distressing is it to be a member of a family that may be at risk for breast cancer?

Not At All Distressing			Very Distressing	
1	2	3	4	5

A test is now available which allows women in high-risk families to find out if they (personally) have the alteration(s) of a gene (BRCA1) associated with increased risk for breast and ovarian cancer.

2j. On a scale from 1 to 5, how distressing is it to be given the opportunity to be tested for this gene?

Not At All Distressing			Very Distressing	
1	2	3	4	5

2k. On a scale from 1 to 5, 1 being "not at all," and 5 being "very much," to what extent do you welcome the opportunity to be tested?

Not At All			Very Much	
1	2	3	4	5

- 2l. On a scale from 1 to 5, with 1 being "not at all distressing," and 5 being "very distressing," how distressing would it be to have the test and discover that you have the altered gene that is associated with an increased risk for breast and ovarian cancer?

Not At All Distressing			Very Distressing	
1	2	3	4	5

- 2m. Using the same scale, how distressing would it be to have the test and discover that you do not have the altered gene?

Not At All Distressing			Very Distressing	
1	2	3	4	5

FOR QUESTIONS 3-5b, INDICATE THE NUMBER OF RELATIVES AFFECTED BY CANCER - ENTER ZERO FOR NO CANCER DIAGNOSIS IN A CATEGORY

		Mother	Sister(s)	Daughter(s)	First Aunt(s)	Grandmother(s)	First Cousin(s)
3.	Which of your relatives has had breast cancer?						
4.	Which of your relatives has had ovarian cancer?						
5a.	Have any of your relatives died of breast cancer?						
5b.	Have any of your relatives died of ovarian cancer?						

NOT INCLUDING
GREAT-
GRANDMOTHERS

RELATIVES AFFECTED BY CANCER:

REPEAT THIS SECTION (QUESTIONS 0-10) FOR EACH RELATIVE R INDICATES AFFECTED BY CANCER

Now I am going to ask you about your experiences with cancer among your close relatives.

Let's Start with _____(relationship)

0. Is she from your mother or your father's side of the family?

Mother's	Father's
1	2

1. When was she diagnosed?

DATE: _____(year)

1a. On a scale from 1 to 5, how distressed were you by her diagnosis?

Not At All Distressed		Very Distressed		
1	2	3	4	5

Didn't Know IF VOL.
6

2. Is she alive?

1. Yes	5. No
--------	-------

IF R ANSWERS "NO" TO 2:

2a. Did she die of the cancer or something related to it?
SCORE R's BELIEF

1. Yes	5. No
--------	-------

IF R ANSWERS "YES" To 2a:

2b. When did she die?

DATE: _____(year)

2c. How old was she when she died?

AGE: _____(years)

2d. How old were you when she died?

AGE: _____(years)

2e. On a scale from 1 to 5, how distressed were you by this news?

Not At All Distressed			Very Distressed	
1	2	3	4	5

Didn't Know IF VOL.
6

3. What treatment did she receive? SCORE EACH SURGERY SEPARATELY

Treatment:	1. Yes	5. No
A. Lumpectomy		
B. Unilateral Mastectomy		
C. Bilateral Mastectomy		
D. Oophorectomy (ovaries removed)		
E. Hysterectomy		
F. Chemotherapy		
G. Radiation		
H. Hormonal Therapy		
I. Immunotherapy		
J. Don't Know		
K. Other		
L. None		

IF BOTH BREASTS REMOVED IN
TWO SEPARATE SURGERIES
SCORE YES FOR UNILATERAL
AND YES FOR BILATERAL

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

		Not At All					Very Much	Didn't Know IF VOL.
4.	At the time of the illness, how (emotionally) close were you to your (relative)?	1	2	3	4	5	6	

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much",

5. At the time of her illness, how aware were you of the following aspects of your (relative's) condition?

	Not at All				Very Much	Didn't Know If Vol
A. Diagnosis	1	2	3	4	5	6
B. Course of illness	1	2	3	4	5	6
C. Prognosis (what could be expected)	1	2	3	4	5	6
D. Her pain or suffering	1	2	3	4	5	6
E. Side effects of treatment	1	2	3	4	5	6
F. Impairment (not being able to do what she once did) and disruption of her life	1	2	3	4	5	6
G. How involved were you in the treatment and care of your (relative)?	1	2	3	4	5	6

6. At the time of her illness, did you help care for her in any of the following ways?

	1. Yes	5. No
A. Accompanied to appointments		
B. Visited at hospital		
C. Did chores for her		
D. Provided comfort and emotional support		

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

	Not At All				Very Much	Didn't Know IF VOL.
7. At that time, to what extent did you talk with her about her experience?	1	2	3	4	5	6
8. At that time, how upsetting was her experience with cancer for you? [OVERALL]	1	2	3	4	5	6

	Much More Distant	A Little More Distant	No Change	A Little Closer	A Lot Closer
9. At that time, how did your (relative's) illness affect your relationship with other family members? Did it make you...[READ OPTIONS]	1	2	3	4	5

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

	Not At All					Very Much	Didn't Know IF VOL.
10. How much has your experience with your (relative) affected the way you think about your own risk for cancer and options for dealing with it? [CURRENTLY]	1	2	3	4	5		6

REPEAT QUESTIONS 0-10 (STARTING ON PAGE 5) FOR ANY ADDITIONAL RELATIVES

11. Now I'd like to find out how you keep up with new information about breast cancer (including prevention, detection, and treatment). I'm going to read you a list of sources; On a scale from 1 to 5, with 1 being "not at all" and 5 being "very much," how much do you rely on... REPEAT AS NECESSARY

	Not At All					Very Much
a. Your OB/GYN	1	2	3	4	5	
b. Your family physician	1	2	3	4	5	
c. Another physician (Specialty_____)	1	2	3	4	5	
d. Family Members [WHO GAVE INFO]	1	2	3	4	5	
e. Friends [WHO GAVE INFO]	1	2	3	4	5	
f. Newspapers, television, and radio	1	2	3	4	5	
g. Popular women's magazines	1	2	3	4	5	
h. Other (specify_____)	1	2	3	4	5	

READ OPTIONS

		Not At All	A Little	Somewhat	A Great Deal
12.	How much do you watch for new information in the media (newspaper, magazines, television, radio)?	1	2	3	4
13.	How much do you try to avoid this information in the media?	1	2	3	4
14.	How much confidence do you have in the accuracy of such information in the media?	1	2	3	4

15bi. Are you aware of the gene (BRCA1) associated with increased risk for early onset breast cancer?

1. Yes	5. No
--------	-------

IF R ANSWERS "YES" TO 15b:

	Hopeful	Relieved	Anxious or Fearful	Depressed
15c. Which of the following best describes how you felt when you heard about the discovery of this gene? READ OPTIONS - R MAY CHOOSE ONLY ONE	1	2	3	4

IF R ANSWERS "YES" TO 15b:

	Not At All	A Little	Somewhat	A Great Deal
15d. How much did you discuss this development with your mother and/or your sisters? READ OPTIONS	1	2	3	4
15e. IF R IS MARRIED/PARTNERED: How much have you discussed this development with your (spouse/partner)? READ OPTIONS	1	2	3	4
15f. IF R HAS CHILDREN: How much have you discussed this development with your children? READ OPTIONS	1	2	3	4

15g. IF R IS CANCER POSITIVE:

Women who are living with breast cancer report various levels of distress.
How often do you feel distressed about living with breast cancer?

IF R IS CANCER NEGATIVE:

Women who are at risk for breast cancer report various levels of distress.
How often do you feel distressed about your risk for breast cancer?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

15h. Thinking about your family's risk for breast cancer and your own diagnosis/risk, what has been the most distressing part?

15i. On a scale from 1 to 5, how distressing is this?

Not At All Distressing			Very Distressing	
1	2	3	4	5

FOR WOMEN WITH LIVING SISTERS:
SKIP IF R HAS NO LIVING SISTERS

Now I'm going to ask some questions about your relationship with your sisters.

16a. IF R IS CANCER POSITIVE:

How often do you discuss living with breast cancer with your sisters?

IF R IS CANCER NEGATIVE:

How often do you discuss your risk for breast cancer with your sisters?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

IF R ANSWERS "NEVER" TO 16a, DO NOT ASK 16b-d

16b. When you have these discussions, who generally initiates them?

You	Your Sisters	Equally [IF VOLUNTEERED]
1	2	3

16c. How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

16d. What is helpful to you when talking with your sisters about your risk for breast cancer?
SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

	1. Yes	5. No
1. Receiving new information.		
2. The opportunity to express your feelings.		
3. Receiving comfort or being taken care of.		
4. Feeling understood.		
5. Knowing you are not alone.		

16e. Overall, how important is your sister's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 16f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your sister's opinion?

IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 16g. Considering **only the positive feelings** you have toward your sisters, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

- 16h. Considering **only the negative feelings** you have toward your sisters, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH LIVING MOTHERS:

SKIP IF R's MOTHER IS NOT LIVING

Now I am going to ask some questions about your relationship with your mother.

- 17a. IF R IS CANCER POSITIVE:

How often do you discuss living with breast cancer with your mother?

IF R IS CANCER NEGATIVE:

How often do you discuss your risk for breast cancer with your mother?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

IF R ANSWERS "NEVER" TO 17a, DO NOT ASK 17b-d

17b. When you have these discussions, who generally initiates them?

You	Your Mother	Equally [IF VOLUNTEERED]
1	2	3

17c. How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17d. What is helpful to you when talking with your mother about your risk for breast cancer?
SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

	1. Yes	5. No
1. Receiving new information.		
2. The opportunity to express your feelings.		
3. Receiving comfort or being taken care of.		
4. Feeling understood.		
5. Knowing you are not alone.		

17e. Overall, how important is your mother's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 17f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your mother's opinion?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 17g. Considering **only the positive feelings** you have toward your mother, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

- 17h. Considering **only the negative feelings** you have toward your mother, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WHO ARE MARRIED OR LIVING WITH A PARTNER:
SKIP IF R IS NOT MARRIED/PARTNERED

Now I am going to ask you some questions about your relationship with your (husband/partner).

- 18a. IF R IS CANCER POSITIVE:

How often do you discuss living with breast cancer with your husband/partner?

IF R IS CANCER NEGATIVE:

How often do you discuss your risk for breast cancer with your husband/partner?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

IF R ANSWERS "NEVER" TO 18a, DO NOT ASK 18b-d

18b. When you have these discussions, who generally initiates them?

You	Your Husband/ Partner	Equally [IF VOLUNTEERED]
1	2	3

18c. How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

18d. What is helpful to you when talking with your husband/partner about your risk for breast cancer?
SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

	1. Yes	5. No
1. Receiving new information.		
2. The opportunity to express your feelings.		
3. Receiving comfort or being taken care of.		
4. Feeling understood.		
5. Knowing you are not alone.		

18e. Overall, how important is your husband/partner's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 18f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your (husband's/partner's) opinion?

IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 18g. Considering **only the positive feelings** you have toward your husband/partner, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

- 18h. Considering **only the negative feelings** you have toward your husband/partner, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH LIVING DAUGHTER/S:
SKIP IF R HAS NO LIVING DAUGHTER/S

Now I am going to ask you some questions about your relationship with your daughter/s.

- 19i. What are the ages of your daughters?

_____	_____	_____
_____	_____	_____
_____	_____	_____

- 19ii. In general, do you discuss family history and risk for breast cancer with your daughter/s?

1. Yes	5. No
--------	-------

- 19e. Overall, how important is/are your daughters' opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 19f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is/are your daughter's opinion/s?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 19g. Considering **only the positive feelings** you have toward your daughters, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

- 19h. Considering **only the negative feelings** you have toward your daughters, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH CHILDREN:
SKIP IF R HAS NO CHILDREN

- 19iii. If you should choose to obtain genetic testing, do you intend to inform your children of the results?

1. Yes	5. No	7. Undecided [IF VOLUNTEERED]
--------	-------	----------------------------------

FOR ALL WOMEN:

20. If you were to find that you were a carrier for BRCA1, the gene for increased risk of breast cancer, what options would you consider?

[DONE]

☐☐☐☐ - ☐



WOMEN'S HEALTH STUDY

Pre-Results Questionnaire

TODAY'S DATE _____

ID _____

PRE-RESULTS ASSESSMENT - U

You may notice that some of these questions were asked in previous questionnaires, but many of the questions are new. We are asking them again because we are interested in feelings and attitudes which may change over time.
THANK YOU VERY MUCH!

GENETIC TESTING-SECTION 1

1. Have you met with anyone to have genetic counseling? B24.
 (1) ☐ Yes (5) ☐ No

2. Has any member of your family met with someone to have genetic counseling? B25.
 (1) ☐ Yes (5) ☐ No

3. As the opportunity to get testing has approached, has your interest in getting results changed? B74.

Decreased Very Much 1	Decreased Slightly 2	No Change 3	Increased Slightly 4	Increased Very Much 5
-------------------------------------	------------------------------------	---------------------------	------------------------------------	-------------------------------------

4. At this time, what is your decision regarding receiving your genetic results? B112.
 (1) ☐ I will probably or definitely receive my results now, as soon as they are offered.
 (Skip to Question 5)

(3) ☐ I do not intend to receive my results now, but may do so later. (Skip to Question 6)

(5) ☐ I do not intend to receive my results now or in the future. (Skip to Question 7)

5. If you will probably or definitely obtain your results **now**, as soon as they are being offered to you, what are your reasons for doing so? B113.
(Please check all that apply and then circle the number of the statement which indicates your most important reason for receiving your results *now*).

- (1) ☐ I just want to know whether I have the gene. I am happier knowing.
 (2) ☐ In order to decide whether to get prophylactic surgery.
 (3) ☐ To assist me in other medical decisions.
 (4) ☐ To make decisions about family planning.
 (5) ☐ To make decisions about financial planning and insurance.
 (6) ☐ To make lifestyle and other non-medical decisions.
 (7) ☐ To find out the risk that may be transmitted to my children.
 (8) ☐ Family members want me to get testing.
 (9) ☐ I want to help other family members by providing them with my results.
 (10) ☐ Other (please describe) _____

6. If you do **not** intend to obtain your results **now**, but may do so **later**, please indicate your reasons. B114.

(Please check all that apply **and** then circle the number of the statement which indicates your most important reason for delaying receiving your results).

- (1) ☐ I am happier not knowing.
- (2) ☐ There are no decisions I need to make at this time for which knowledge of my results would be useful.
- (3) ☐ It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) ☐ Knowing that I have a mutation would interfere with my life as it is now.
- (5) ☐ There would not be much I could now do to reduce my risk of cancer if I found out I had a mutation.
- (6) ☐ I am too worried about the effects of knowing my results on women in my family.
- (7) ☐ Family members do not want me to get testing.
- (8) ☐ Family members want me to get testing, but I am not ready to do so.
- (9) ☐ I want to wait until there is less risk to insurance coverage.
- (10) ☐ I want to wait until there is less risk to employment.
- (11) ☐ I am either too young or too old to benefit from knowing if I have a mutation.
- (12) ☐ I want to wait until more is known about breast/ovarian cancer genes and what can be done to reduce a women's risk of cancer.
- (13) ☐ I simply am not ready to make up my mind at this time.
- (14) ☐ Other (please describe) _____

7. If you do **not** intend to obtain your results **now or in the future**, please indicate your reasons. B115.
(Please check all that apply **and** then circle the number of the statement which indicates your most important reason for not receiving your results).

- (1) ☐ I am happier not knowing.
- (2) ☐ There are no decisions I need to make for which knowledge of my results would be useful.
- (3) ☐ It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) ☐ Knowing that I have a mutation would interfere with my life.
- (5) ☐ There would not be much I could do to reduce my risk of cancer if I found out I had a mutation.
- (6) ☐ I am too worried about the effects of knowing my results on women in my family.
- (7) ☐ Family members do not want me to get testing.
- (8) ☐ Risk to my insurance coverage.
- (9) ☐ Risk to my employment.
- (10) ☐ I am either too young or too old to benefit from knowing if I have a mutation.
- (11) ☐ I do not believe in obtaining personal genetic information.
- (12) ☐ Other (please describe) _____

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

GENETIC TESTING-SECTION 2

Using the following scales, please circle your response for each question.

		<div style="display: flex; justify-content: space-between;"> <i>Not At All</i> <i>Very Much</i> </div>					<i>Not Appli- cable</i>	
		1	2	3	4	5	-8	
1.	How distressing is it for you to know that you may be at increased risk for breast or ovarian cancer because of your family history?							B66.
2.	How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer?							B67.
3.	How distressed do you expect to be if you get tested for an altered BRCA-1/BRCA2 gene (just before you receive results)?							B68.
4.	How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene?							B69.
5.	How distressed would you be if you took the test and found that you did not have an altered BRCA1/BRCA2 gene?							B70.
6.	Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA-1/BRCA2 gene?							B71.

		<div style="display: flex; justify-content: space-between;"> <i>Not At All</i> <i>All The Time</i> </div>					
		1	2	3	4	5	
7.	How often do you worry about developing breast or ovarian cancer?						B27.
8.	To what extent do these worries interfere with your every day life?						B28.
9.	How often do you worry about having an altered gene which conveys heightened risk for breast and ovarian cancer ?						B29.
10.	To what extent do these worries you have about having this altered gene interfere with your every day life?						B30.

11. When was the last time you had a mammogram? B32.

(Month/Year) _____ ☐ (-8) Does not apply because of surgery.

12. How many times have you conducted a breast self-examination in the past six months? B33.
 _____ times ☐ (-8) Does not apply because of surgery.

13. How confident are you that you will perform breast self examination (BSE) ---

13a. --as **frequently** as needed? (-8) ☐ Does Not Apply Because of Surgery. B34a.

Not at All 2 3 4 5 6 7 Very Much So

13b. --as **carefully and competently** as needed? B34b.

(-8) ☐ Does Not Apply Because of Surgery

Not at All 2 3 4 5 6 7 Very Much So

For each of the following areas of your life, we ask you to make **two** ratings. First, indicate how much these decisions have been affected by being at risk for breast or ovarian cancer (based on your family history). Second, how much these decisions would be affected by the results of genetic testing?

1	2	3	4	5
Not at all affected				Very much affected

		<u>Have been affected by being at risk for breast or ovarian cancer</u>					<u>Would be affected by the results of genetic testing</u>					
		1	2	3	4	5	1	2	3	4	5	
14.	Decisions about having children											B35a B35b
15.	Decisions about form of birth control											B36a B36b
16.	Decisions about which steps to take to prevent the occurrence of breast or ovarian cancer											B37a B37b
17.	Decisions about work and career											B38a B38b
18.	Decisions about savings and financial planning											B39a B39b
19.	Decisions about plans for the future											B40a B40b

20. **Answer the following question only if you have daughters.**

☐ Does Not Apply (Skip to the next question, 22)

B41.

		<u>Have been affected by being at high risk for breast or ovarian cancer</u>					<u>Would be affected by the results of genetic testing</u>					
a-b.		1	2	3	4	5	1	2	3	4	5	B42 a/b
	Plans for your daughter's future											

21. Do you feel you have enough information about breast or ovarian cancer to make any decisions that might be necessary?

Not At All						Very Much
1	2	3	4	5	6	7

B43.

22. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast and ovarian cancer?

Not At All						Very Much
1	2	3	4	5	6	7

B44.

23. Do you feel you are adequately informed about what you could do to reduce your risk of breast and ovarian cancer if you had an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B45.

24. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B46.

25. Do you feel you are adequately informed about what it would mean for your children if you had an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B47.

26. How confident are you that you will make the best decision in deciding whether to be tested for BRCA1/BRCA2?

Not At All						Very Much
1	2	3	4	5	6	7

B48a.

27. How confident are you that you would cope effectively with a finding that you had an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48b.

28. How confident are you that you would make the best decision concerning your options if you were found to have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48c.

29. How confident are you that you would be able to follow through and cope effectively over the long haul if you were found to have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48d.

RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.
(1) ☐ Yes (5) ☐ No
2. If married, can you share your most private feelings with your spouse/partner without holding back? C21a.
(1) ☐ Yes (5) ☐ No
3. If married, is there anyone besides your spouse/partner with whom you can share your most private feelings without holding back? C21b.
(1) ☐ Yes (5) ☐ No
-

LIFE EVENTS SECTION

1. Have any of the following events happened to you in the past six months? D1(a-m)
(Please Check All That Apply)
- | | |
|--|---|
| a. <input type="checkbox"/> You retired, were fired, or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce |
| c. <input type="checkbox"/> Your spouse retired, was fired, or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles or difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> You were seriously ill or injured. |
-

MARRIAGE SECTION

The following questions apply to persons who are married or living with a partner. If you are not married or living with a partner, please check the box and skip to page 11, Mood Section.

Not married or living with a partner ☐

Ea.

Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your spouse/partner **DURING THE PAST MONTH**.

		<i>Always Disagree</i>	<i>Almost Always Disagree</i>	<i>Fre- quently Disagree</i>	<i>Occa- sionally Disagree</i>	<i>Almost Always Agree</i>	<i>Always Agree</i>	
1.	Religious matters	1	2	3	4	5	6	H3.
2.	Demonstration of affection	1	2	3	4	5	6	H4.
3.	Sex relations	1	2	3	4	5	6	H6.
4.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	H7.
5.	Making major decisions	1	2	3	4	5	6	H12.
6.	Career decisions	1	2	3	4	5	6	H15.

		<i>Never</i>	<i>Rarely</i>	<i>Occa- sionally</i>	<i>More often than most</i>	<i>Most of the time</i>	<i>All of the time</i>	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
8.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.
9.	How often do you and your partner quarrel?	1	2	3	4	5	6	H21.
10.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

		<i>None of Them</i>	<i>Very Few of Them</i>	<i>Some of Them</i>	<i>Most of Them</i>	<i>All of Them</i>
11.	To what extent do you and your spouse/partner share interests together?	1	2	3	4	5

H24.

How often would you say the following events occur between you and your spouse/partner?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

15. Considering **only the positive feelings** you have towards your spouse/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

H33.

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

16. Considering **only the negative feelings** you have towards your spouse/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your spouse/partner's involvement in your health care.

		<i>Never</i> <i>Very Often</i>				
a.	How often does your spouse/partner go with you to your appointments with doctors?	1	2	3	4	5
b.	How often does your spouse/partner talk with your doctor or other medical personnel about your risk for breast or ovarian cancer?	1	2	3	4	5
c.	How often does your spouse/partner keep track of what you need to do about your risk for breast or ovarian cancer?	1	2	3	4	5
d.	How often does your spouse/partner change their activities to assist you in your health care?	1	2	3	4	5

H35a.

H35b.

H35c.

H35d.

18. Has your spouse/partner attended individual, family or group sessions to become informed about your risk for breast or ovarian cancer and what can be done? H36.
 (1) ☐ Yes (5) ☐ No

19. How much contact has your spouse/partner had with medical personnel concerning your risk for breast or ovarian cancer? H37.

Very Little or None							A lot
1	2	3	4	5	6	7	

20. Do you feel your spouse/partner is adequately informed concerning your risk for breast or ovarian cancer and what can be done about it? H38.

Not at All						Very Much
1	2	3	4	5	6	7

21. To what extent are you satisfied with your spouse/partner's involvement in your health care? H39.

Not at All						Very Much
1	2	3	4	5	6	7

MOOD SECTION

1. In the past year, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
 (1) ☐ Yes (5) ☐ No (Skip to Question 2)

1a. During this period, did your work or relationships suffer? I12a.
 (1) ☐ Yes (5) ☐ No

1b. During this period, did you get counseling or psychotherapy? I12b.
 (1) ☐ Yes (5) ☐ No

1c. During this period, did you get medication for this condition? I12c.
 (1) ☐ Yes (5) ☐ No

2. Are you **currently** receiving counseling, psychotherapy, or medication for depression or emotional problems? I13.
 (1) ☐ Yes (5) ☐ No

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast or ovarian cancer. For each of the statements below, indicate the degree to which your life is affected positively by your risk of breast or ovarian cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast or ovarian cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Please make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4
c.	I've been saying to myself "this isn't possible."	1	2	3	4
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
e.	I've been getting emotional support from others.	1	2	3	4
f.	I've been giving up trying to deal with it.	1	2	3	4
g.	I've been taking action to try to make the situation better.	1	2	3	4
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4
m.	I've been getting comfort and understanding from someone.	1	2	3	4

L7a.

L7b.

L7c.

L7d.

L7e.

L7f.

L7g.

L7h.

L7i.

L7j.

L7k.

L7l.

L7m.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
n.	I've been giving up the attempt to cope.	1	2	3	4
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4
p.	I've been expressing my negative feelings.	1	2	3	4
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4
s.	I've been thinking hard about what steps to take.	1	2	3	4
t.	I've been praying or meditating.	1	2	3	4
u.	I've been making fun of the situation.	1	2	3	4

L7n.

L7o.

L7p.

L7q.

L7r.

L7s.

L7t.

L7u.

3. The following items are to be answered only by those women who are married or living with a partner.

☐ Not married or living with a partner

L8.

(Skip to the last section on next page)

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
a.	I've been denying or hiding my anger around my spouse/partner.	1	2	3	4
b.	I've been denying or hiding my worries around my spouse/partner.	1	2	3	4
c.	I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4
d.	I've acted more positive around my spouse/partner than I feel.	1	2	3	4

L8a.

L8b.

L8c.

L8d.

BACKGROUND DATA SECTION

These are a few questions about your religious background that we forgot to ask on the original questionnaire.

1. Religion: Catholic (1) ☐ Protestant (4) ☐ **A 3.**
Jewish (2) ☐ Buddhist (5) ☐
Muslim (3) ☐ Other (6) ☐
None (7) ☐
- 1a. How often do you attend religious services? **A 3a.**
(1) (5)
☐ Less Often Than Once a Month ☐ A Few Times A Month or More
- 1b. How important are religious and spiritual beliefs in your life? **A 3b.**
Not at All 2 3 4 Very Important
1 5

Once again, We thank you for all of your valued participation in this study.

-



WOMEN'S HEALTH STUDY

Pre-Results Questionnaire

TODAY'S DATE _____

ID _____

PRE-RESULTS QUESTIONNAIRE - A

You may notice that some of these questions were asked in previous questionnaires, but many of the questions are new. We are asking them again because we are interested in feelings and attitudes which may change over time.
THANK YOU VERY MUCH!

GENETIC TESTING-SECTION 1

1. Have you met with anyone to have genetic counseling?
(1) ☐ Yes (5) ☐ No

B24.

2. Has any member of your family met with someone to have genetic counseling?
(1) ☐ Yes (5) ☐ No

B25.

3. As the opportunity to get testing has approached, has your interest in getting results changed?

B74.

Decreased Very Much 1	Decreased Slightly 2	No Change 3	Increased Slightly 4	Increased Very Much 5
-------------------------------------	------------------------------------	---------------------------	------------------------------------	-------------------------------------

4. At this time, what is your decision regarding receiving your genetic results?
(1) ☐ I will probably or definitely receive my results now, as soon as they are offered.
(Skip to Question 5)

B112.

(3) ☐ I do not intend to receive my results now, but may do so later. (Skip to Question 6)

(5) ☐ I do not intend to receive my results now or in the future. (Skip to Question 7)

5. If you will probably or definitely obtain your results now, as soon as they are being offered to you, what are your reasons for doing so?
(Please check all that apply and then circle the number of the statement which indicates your most important reason for receiving your results now).

B113.

- (1) ☐ I just want to know whether I have the gene. I am happier knowing.
(2) ☐ In order to decide whether to get prophylactic surgery.
(3) ☐ To assist me in other medical decisions.
(4) ☐ To make decisions about family planning.
(5) ☐ To make decisions about financial planning and insurance.
(6) ☐ To make lifestyle and other non-medical decisions.
(7) ☐ To find out the risk that may be transmitted to my children.
(8) ☐ Family members want me to get testing.
(9) ☐ I want to help other family members by providing them with my results.
(10) ☐ Other (please describe) _____

6. If you do not intend to obtain your results now, but may do so later, please indicate your reasons. **B114.**
(Please check all that apply and then circle the number of the statement which indicates your most important reason for delaying receiving your results).

- (1) ☐ I am happier not knowing.
- (2) ☐ There are no decisions I need to make at this time for which knowledge of my results would be useful.
- (3) ☐ It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) ☐ Knowing that I have a mutation would interfere with my life as it is now.
- (5) ☐ There would not be much I could now do to reduce my risk of cancer if I found out I had a mutation.
- (6) ☐ I am too worried about the effects of knowing my results on women in my family.
- (7) ☐ Family members do not want me to get testing.
- (8) ☐ Family members want me to get testing, but I am not ready to do so.
- (9) ☐ I want to wait until there is less risk to insurance coverage.
- (10) ☐ I want to wait until there is less risk to employment.
- (11) ☐ I am either too young or too old to benefit from knowing if I have a mutation.
- (12) ☐ I want to wait until more is known about breast/ovarian cancer genes and what can be done to reduce a women's risk of cancer.
- (13) ☐ I simply am not ready to make up my mind at this time.
- (14) ☐ Other (please describe) _____

7. If you do not intend to obtain your results now or in the future, please indicate your reasons. **B115.**
(Please check all that apply and then circle the number of the statement which indicates your most important reason for not receiving your results).

- (1) ☐ I am happier not knowing.
- (2) ☐ There are no decisions I need to make for which knowledge of my results would be useful.
- (3) ☐ It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) ☐ Knowing that I have a mutation would interfere with my life.
- (5) ☐ There would not be much I could do to reduce my risk of cancer if I found out I had a mutation.
- (6) ☐ I am too worried about the effects of knowing my results on women in my family.
- (7) ☐ Family members do not want me to get testing.
- (8) ☐ Risk to my insurance coverage.
- (9) ☐ Risk to my employment.
- (10) ☐ I am either too young or too old to benefit from knowing if I have a mutation.
- (11) ☐ I do not believe in obtaining personal genetic information.
- (12) ☐ Other (please describe) _____

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	If you don't have your health, you don't have anything.						L5a.
b.	There are many things I care about more than my health.						L5b.
c.	Good health is of only minor importance in a happy life.						L5c.
d.	There is nothing more important than good health.						L5d.
e.	In uncertain times, I usually expect the best.						E1.
f.	It's easy for me to relax.						E2.
g.	If something can go wrong for me, it will.						E3.
h.	I always look on the bright side of things.						E4.
i.	I'm always optimistic about my future.						E5.
j.	I enjoy my friends a lot.						E6.
k.	It's important for me to keep busy.						E7.
l.	I hardly ever expect things to go my way.						E8.
m.	Things never work out the way I want them to.						E9.
n.	I don't get upset too easily.						E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."						E11.
p.	I rarely count on good things happening to me.						E12.

GENETIC TESTING-SECTION 2

Using the following scales, please circle your response for each question.

		Not At All					Very Much	Not Appli- cable	
1.	How distressing is it for you to know that you may be at increased risk for recurrence of breast or ovarian cancer because of your family history?	1	2	3	4	5	-8		B 66.
2.	How distressing is it to be given the opportunity to be tested for an altered BRCA1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer?	1	2	3	4	5	-8		B 67.
3.	How distressed do you expect to be if you get tested for an altered BRCA1/BRCA2 gene (just before you receive results)?	1	2	3	4	5	-8		B 68.
4.	How distressed would you be if you took the test and found that you had an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8		B 69.
5.	How distressed would you be if you took the test and found that you did not have an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8		B 70.
6.	Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8		B 71.

		Not At All			All The Time		
7.	How often do you worry about again developing breast or ovarian cancer?	1	2	3	4	5	B 27.
8.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B 28.
9.	How often do you worry about having an altered gene which conveys heightened risk for breast and ovarian cancer ?	1	2	3	4	5	B 29.
10.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B 30.

11. When was the last time you had a mammogram? B 32.

(Month/Year) _____ ☐ (-8) Does not apply because of surgery.

12. How many times have you conducted a breast self-examination in the past six months? B33.
 _____ times ☐ (-8) Does not apply because of surgery.

13. How confident are you that you will perform breast self examination (BSE) ---

13a. --as **frequently** as needed? (-8) ☐ Does Not Apply Because of Surgery. B34a.

Not at All Very Much So
 1 2 3 4 5 6 7

13b. --as **carefully and competently** as needed? B34b.

(-8) ☐ Does Not Apply Because of Surgery

Not at All Very Much So
 1 2 3 4 5 6 7

For each of the following areas of your life, we ask you to make **two** ratings. First, indicate how much these decisions have been affected by being at increased risk for breast or ovarian cancer (based on your family history). Second, how much these decisions would be affected by the results of genetic testing?

1	2	3	4	5
Not at all affected				Very much affected

		<u>Have been affected by being at increased risk for breast or ovarian cancer</u>					<u>Would be affected by the results of genetic testing</u>					
		1	2	3	4	5	1	2	3	4	5	
14.	Decisions about having children											B35a B35b
15.	Decisions about form of birth control											B36a B36b
16.	Decisions about which steps to take to prevent the recurrence of breast or ovarian cancer											B37a B37b
17.	Decisions about work and career											B38a B38b
18.	Decisions about savings and financial planning											B39a B39b
19.	Decisions about plans for the future											B40a B40b

20. Answer the following question only if you have daughters.
☐ Does Not Apply (Skip to the next question, 22)

B41.

		<u>Have been affected by being at high risk for breast or ovarian cancer</u>					<u>Would be affected by the results of genetic testing</u>					B42 a/b
a-b.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	

21. Do you feel you have enough information about breast or ovarian cancer to make any decisions that might be necessary?

Not At All						Very Much
1	2	3	4	5	6	7

B43.

22. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast and ovarian cancer?

Not At All						Very Much
1	2	3	4	5	6	7

B44.

23. Do you feel you are adequately informed about what you could do to reduce your risk of recurrence of breast and ovarian cancer if you had an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B45.

24. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B46.

25. Do you feel you are adequately informed about what it would mean for your children if you had an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B47.

26. How confident are you that you will make the best decision in deciding whether to be tested for BRCA1/BRCA2?

Not At All						Very Much
1	2	3	4	5	6	7

B48a.

27. How confident are you that you would cope effectively with a finding that you had an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48b.

28. How confident are you that you would make the best decision concerning your options if you were found to have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48c.

29. How confident are you that you would be able to follow through and cope effectively over the long haul if you were found to have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48d.

RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings without holding back? **C21.**
(1) ☐ Yes (5) ☐ No
2. If married, can you share your most private feelings with your spouse/partner without holding back? **C21a.**
(1) ☐ Yes (5) ☐ No
3. If married, is there anyone besides your spouse/partner with whom you can share your most private feelings without holding back? **C21b.**
(1) ☐ Yes (5) ☐ No
-

LIFE EVENTS SECTION

1. Have any of the following events happened to you in the past six months? **D1(a-m)**
(Please Check All That Apply)
- | | |
|--|---|
| a. <input type="checkbox"/> You retired, were fired, or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce |
| c. <input type="checkbox"/> Your spouse retired, was fired, or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles or difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> You were seriously ill or injured. |
-

MARRIAGE SECTION

The following questions apply to persons who are married or living with a partner. If you are not married or living with a partner, please check the box and skip to page 11, Mood Section.

Not married or living with a partner ☐

Ea.

Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your spouse/partner **DURING THE PAST MONTH.**

		<i>Always Disagree</i>	<i>Almost Always Disagree</i>	<i>Fre- quently Disagree</i>	<i>Occa- sionally Disagree</i>	<i>Almost Always Agree</i>	<i>Always Agree</i>
1.	Religious matters	1	2	3	4	5	6
2.	Demonstration of affection	1	2	3	4	5	6
3.	Sex relations	1	2	3	4	5	6
4.	Conventionality (correct or proper behavior)	1	2	3	4	5	6
5.	Making major decisions	1	2	3	4	5	6
6.	Career decisions	1	2	3	4	5	6

H3.

H4.

H6.

H7.

H12.

H15.

		<i>Never</i>	<i>Rarely</i>	<i>Occa- sionally</i>	<i>More often than most</i>	<i>Most of the time</i>	<i>All of the time</i>
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6
8.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6
9.	How often do you and your partner quarrel?	1	2	3	4	5	6
10.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6

H16.

H20.

H21.

H22.

		<i>None of Them</i>	<i>Very Few of Them</i>	<i>Some of Them</i>	<i>Most of Them</i>	<i>All of Them</i>
11.	To what extent do you and your spouse/partner share interests together?	1	2	3	4	5

H24.

How often would you say the following events occur between you and your spouse/partner?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

15. Considering **only the positive feelings** you have towards your spouse/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

H33.

Not At All Positive									Extremely Positive
1	2	3	4	5	6	7	8	9	10

16. Considering **only the negative feelings** you have towards your spouse/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative									Extremely Negative
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your spouse/partner's involvement in your health care.

		Never					Very Often
a.	How often does your spouse/partner go with you to your appointments with doctors?	1	2	3	4	5	
b.	How often does your spouse/partner talk with your doctor or other medical personnel about your risk of breast or ovarian cancer?	1	2	3	4	5	
c.	How often does your spouse/partner keep track of what you need to do about your risk for breast or ovarian cancer?	1	2	3	4	5	
d.	How often does your spouse/partner change their activities to assist you in your health care?	1	2	3	4	5	

H35a.

H35b.

H35c.

H35d.

18. Has your spouse/partner attended individual, family or group sessions to become informed about your risk for breast or ovarian cancer and what can be done? H36.
 (1) ☐ Yes (5) ☐ No

19. How much contact has your spouse/partner had with medical personnel concerning your risk for breast or ovarian cancer? H37.

Very Little or None							A lot
1	2	3	4	5	6	7	

20. Do you feel your spouse/partner is adequately informed concerning your risk for breast or ovarian cancer and what can be done about it? H38.

Not at All						Very Much
1	2	3	4	5	6	7

21. To what extent are you satisfied with your spouse/partner's involvement in your health care? H39.

Not at All						Very Much
1	2	3	4	5	6	7

MOOD SECTION

1. In the past year, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
 (1) ☐ Yes (5) ☐ No (Skip to Question 2)

1a. During this period, did your work or relationships suffer? I12a.
 (1) ☐ Yes (5) ☐ No

1b. During this period, did you get counseling or psychotherapy? I12b.
 (1) ☐ Yes (5) ☐ No

1c. During this period, did you get medication for this condition? I12c.
 (1) ☐ Yes (5) ☐ No

2. Are you currently receiving counseling, psychotherapy, or medication for depression or emotional problems? I13.
 (1) ☐ Yes (5) ☐ No

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the Past Three Months.*

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast or ovarian cancer. For each of the statements below, indicate the degree to which your life is affected positively by your risk of breast or ovarian cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast or ovarian cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Please make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4	L7o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7q.
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4	L7r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7s.
t.	I've been praying or meditating.	1	2	3	4	L7t.
u.	I've been making fun of the situation.	1	2	3	4	L7u.

3. The following items are to be answered only by those women who are married or living with a partner.

☐ Not married or living with a partner

(Skip to the last section on next page)

L8.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been denying or hiding my anger around my spouse/partner.	1	2	3	4	L8a.
b.	I've been denying or hiding my worries around my spouse/partner.	1	2	3	4	L8b.
c.	I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4	L8c.
d.	I've acted more positive around my spouse/partner than I feel.	1	2	3	4	L8d.

BACKGROUND DATA SECTION

These are a few questions about your religious background that we forgot to ask on the original questionnaire.

1. Religion: Catholic (1) ☐ Protestant (4) ☐ **A 3.**
Jewish (2) ☐ Buddhist (5) ☐
Muslim (3) ☐ Other (6) ☐
None (7) ☐

- 1a. How often do you attend religious services? **A 3a.**
(1) (5)
☐ Less Often Than Once a Month ☐ A Few Times A Month or More

- 1b. How important are religious and spiritual beliefs in your life? **A 3b.**
Not at All 2 3 4 Very Important
1 5

Once again, We thank you for all of your valued participation in this study.

TODAY'S DATE _____

ID _____

POST-RESULTS.1 INTERVIEW—*One to Two Month Follow-Up*

INTERVIEWER: For the Introduction, Please include the following important points or read the script:

- Thank the subject again for her participation (We know we've asked a lot of her.)
- This interview is one to two months after receiving genetic test results.
- Repetition of Questions needed to compare results to our previous research and to other researchers.
- Remind subject that this interview is confidential and completely voluntary.
- Suggest that the subject may prefer to get a pen and paper to jot down the different scales that will be used.

We have asked you a lot of questions over the last several years while you were waiting for your genetic results. This interview is scheduled one to two months after you received genetic test results. We recognize that we asked many of these questions before. They are the "gold" standards in this kind of research and in order to compare our results with other researchers we need to ask them again. As you know, offering of genetic testing for breast and ovarian cancer is still relatively new and genetic counselors rely on research like this to plan services. We know that we've asked a lot of you. Thanks again for all your patience.

(1) ☐ Affected (0) ☐ Unaffected



For AFFECTED Subjects Only:

1. First of all...Before your own diagnosis of cancer (breast or ovarian), Did you believe that you were a member of a family at high risk for breast and ovarian cancer?

(1) ☐ Yes (5) ☐ No

N1

POST-RESULTS 1: *One to Two Months***Genetic Testing Section**

1. When did you receive your results of genetic testing? _____ B101
2. Are you the only person in your family who has gotten genetic testing for breast and ovarian cancer?
(1) ☐ Yes (5) ☐ No B101a
3. What were the results of testing? B101b
- 1 ☐ Negative (uninformative) for BRCA1/BRCA2 and all Family members who were tested were negative for BRCA1/BRCA2 OR you are the only person in your family who has gotten testing (Skip to Question 4)
- 2 ☐ Negative (informative) for BRCA1/BRCA2, but at least one family member was found to be Positive (Skip to Question 4)
- 3 ☐ Positive for BRCA1/BRCA2 (Skip to Next page, Question 5)
4. When you took the test and found out that you did not have an altered gene associated with high risk for breast and ovarian cancer, what were your reactions?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>			<i>N/A</i>	
a.	I felt wonderful.	1	2	3	4	5	-8		B18a_a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	-8		B18a_b.
c.	I felt relieved.	1	2	3	4	5	-8		B18a_c.
d.	I did not believe the results.	1	2	3	4	5	-8		B18a_d.
e.	I fell apart emotionally.	1	2	3	4	5	-8		B18a_e.
f.	I felt guilty.	1	2	3	4	5	-8		B18a_f.
g.	I still felt anxious.	1	2	3	4	5	-8		B18a_g.
h.	I felt angry.	1	2	3	4	5	-8		B18a_h.
i.	I felt prepared for the future.	1	2	3	4	5	-8		B18a_i.
j.	I felt I had done all I needed to do.	1	2	3	4	5	-8		B18a_j.
k.	I did not feel very differently.	1	2	3	4	5	-8		B18a_k.

INTERVIEWER: Skip to Page 3, Question 6

5. When you took the test and found out that you had an altered gene associated with high risk for breast and ovarian cancer, what were your reactions?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>			<i>N/A</i>	
a.	I felt relieved about being more certain.	1	2	3	4	5	-8		B19a_a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	-8		B19a_b.
c.	I did not believe the results.	1	2	3	4	5	-8		B19a_c.
d.	I felt guilty.	1	2	3	4	5	-8		B19a_d.
e.	I felt depressed.	1	2	3	4	5	-8		B19a_e.
f.	I felt worried about the future.	1	2	3	4	5	-8		B19a_f.
g.	I fell apart emotionally.	1	2	3	4	5	-8		B19a_g.
h.	I felt anxious.	1	2	3	4	5	-8		B19a_h.
i.	I felt angry.	1	2	3	4	5	-8		B19a_i.
j.	I did not feel very differently.	1	2	3	4	5	-8		B19a_j.
k.	[For those who have daughters]. I wanted my daughters to be tested as soon as possible.	1	2	3	4	5	-8		B19a_k.

6. I am going to read a list of comments made by people after they have received their genetic test results. When you hear each comment, think about your thoughts and feelings toward the test results in terms of you. Please tell me how often each of the comments was true for you since you have received your test results, with the choices of *Not at All*, *Rarely*, *Sometimes*, and *Often*.

(INTERVIEWER NOTE: "IT" in the following questions refers to "RECEIVING TEST RESULTS")

		Not at All	Rarely	Sometimes	Often	
a.	I thought about it when I didn't mean to.	0	1	3	5	B116a.
b.	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	3	5	B116b.
c.	I tried to remove it from memory.	0	1	3	5	B116c.
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.	0	1	3	5	B116d.
e.	I had waves of strong feelings about it.	0	1	3	5	B116e.
f.	I had dreams about it.	0	1	3	5	B116f.
g.	I stayed away from reminders of it.	0	1	3	5	B116g.
h.	I felt as if it hadn't happened or it wasn't real.	0	1	3	5	B116h.
i.	I tried not to talk about it.	0	1	3	5	B116i.
j.	Pictures about it popped into my mind.	0	1	3	5	B116j.
k.	Other things kept making me think about it.	0	1	3	5	B116k.
l.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	3	5	B116l.
m.	I tried not to think about it.	0	1	3	5	B116m.
n.	Any reminder brought back feelings about it.	0	1	3	5	B116n.
o.	My feelings about it were kind of numb.	0	1	3	5	B116o.

Please answer the following two questions using a 1-5 scale, where 1=Not at All and 5=All the time

		Not At All All The Time					
7	How often do you worry about developing breast cancer OR developing breast cancer again?	1	2	3	4	5	B27.
8.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.

Symptoms of Strain Section

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please listen to each one carefully and tell me the answer which best reflects how much that symptom has bothered you during the **PAST THREE MONTHS**. Please use the following scale: 1=Not at all, 2=A little, 3=Quite a bit, and 4=Extremely.

		<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
19.	Feeling blue	1	2	3	4	K19.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

26. Are the symptoms we just talked about related to your receiving your genetic test results?

Yes	No
1	5

K26

Open-ended Questions:

1. Do you feel you were given adequate information before receiving your genetic results? B117.

- 1a. Was there anything omitted that would have been helpful? B117a.

- 1b. What information was most helpful? B117b.

2. What was the most effective or helpful thing you did to cope during this process?

B118.

3. Were there any things you did that were not helpful? What were they?

B119.

4. Who has been the most helpful during this time? (Make a listing in order R gives you)

B120.

1. _____	5. _____
2. _____	6. _____
3. _____	7. _____
4. _____	8. _____

4a. If the list has more than one person, Who has been most helpful?

B120a.

4b. What did they do for you?

B120b.

5. Has there been anything someone did that was not helpful?

B121.

6. Are you currently Married or Living in a steady marriage-like relationship?

B122.

(1) ☐ Yes

(5) ☐ No (Skip to next page, question 9)

If YES and R has not yet discussed her spouse/partner's support:

7. What's the most helpful thing your spouse/partner has done or is doing for you?

B123.

8. What's the most helpful thing your spouse could do for you?

B124.

9. Is there anything you plan to do immediately with this information?

B125.

10. What would you tell someone who is contemplating genetic testing?

B126.

11. Do you have any regrets about getting this testing? If yes, what are they?

B127.

12. Are you the first person in your family to get testing?

B128.

13. Will you encourage your relatives to get genetic testing or discourage them from testing?

B129.

14. We are trying to get a better picture of this process. What is something I didn't ask you that I should have?

B130.

POST-RESULTS INTERVIEW--*Six Month Follow-Up*

INTERVIEWER: For the Introduction, Please include the following important points or read the script:

- Thank the subject again for her participation (We know we've asked a lot of her.)
- This interview is 6 months after receiving genetic test results.
- Repetition of Questions needed to compare results to our previous research and to other researchers.
- Remind subject that this interview is confidential and completely voluntary.
- Suggest that the subject may prefer to get a pen and paper to jot down the different scales that will be used.

We have asked you a lot of questions over the last several years while you were waiting for your genetic results. This interview is scheduled 6 months after you received genetic test results. We recognize that we asked many of these questions before. They are the "gold" standards in this kind of research and in order to compare our results with other researchers we need to ask them again. As you know, offering of genetic testing for breast and ovarian cancer is still relatively new and genetic counselors rely on research like this to plan services. We know that we've asked a lot of you. Thanks again for all your patience.

(1) ☐ Affected (0) ☐ Unaffected

For AFFECTED Subjects Only:

1. First of all...Before your own diagnosis of cancer (breast or ovarian), Did you believe that you were a member of a family at high risk for breast and ovarian cancer?

(1) ☐ Yes (5) ☐ No

N1

Researchers are always interested in stress.

Standardized measures of stressful life events have been established with 0 representing no stress and 100 representing the greatest stress. To give you some reference points, here are some examples:

Change in residence is assigned a stress score of 20

Pregnancy is 40

Death of a close family member is 63

Death of a spouse is 100

Keeping in mind the ratings I just mentioned:

2. How would you rate the stress of being a member of a family at increased risk of breast and ovarian cancer? N2

Being a member of a high risk family _____

3.

<u>UNAFFECTED:</u>	<u>AFFECTED:</u>
Hypothetically....	Thinking about when you were first diagnosed with cancer (breast or ovarian)...

How would you rate the stress of being diagnosed with cancer?

Diagnosis of cancer _____

N3

4. Now, how would you rate the stress of receiving your test results? [By that, I only am referring to the time at which you actually received your results.]

Stress of receiving results _____

N4

5. When you signed up for the study and gave your blood sample, rate how stressful you thought receiving your test results would be?

Stress you had thought getting your test results WOULD be _____

N5

6. Some women tell us that the whole process of getting results went very smoothly, while others tell us that it was an ordeal. Women have been both pleased and annoyed by the information they received or did not receive, the way results were given - that sort of thing. Using our stress ratings, how would you rate the process you went through to get results?

Process to get results _____

N6

- 6a. What about the process has been stressful? Do you have any suggestions for how the process could be improved? N6a

(more space over) _____

Next, we are interested in any recent events in your family related to cancer and risk for cancer. In the past 6 months...

7. To your knowledge, have any of your family members received genetic test results in the past 6 months? What is their relationship to you? Do you know if a mutation was found? Positive or Negative?

(1) ☐ Yes (5) ☐ No (Skip to Next Question)

Total # Received Results: _____

N8t

	Relationship to R:	Positive Mutation Found	Negative No Mutation Found	Don't Know
a.		1	0	-9
b.		1	0	-9
c.		1	0	-9

N8a

N8b

N8c

8. Have any family members declined receiving test results (in the past 6 months)?

(1) ☐ Yes (5) ☐ No (Skip to Next Question)

Total # Declined Results: _____

N9t

	Relationship to R:
a.	
b.	
c.	

N9a

N9b

N9c

9. Have any family members received a new diagnosis of cancer (in the past 6 months)?

(1) ☐ Yes (5) ☐ No (Skip to Next Question)

Total # New Diagnosis: _____

N10t

	Relationship to R:
a.	
b.	
c.	

N10a

N10b

N10c

10. Have any family members had prophylactic surgery (in the past 6 months)?

(1) ☐ Yes (5) ☐ No (Skip to Next Question)

Total # Prophylactic Surgery: _____

N11

	Relationship to R:	Prophylactic Procedure:	
a.			N11a
b.			N11b
c.			N11c

11. Have any family members had any other things happen related to cancer or risk of cancer (in the past 6 months)? [such as treatment, surgery, or death?]

(1) ☐ Yes (5) ☐ No (Skip to Next Question)

Total # Family Members with a Cancer Related Event: _____

N12

	Relationship to R:	Event related to cancer:	
a.			N12a
b.			N12b
c.			N12c

12. Using a 5 point scale where 1=Not at All, 2-Rarely, 3=Sometimes, 4=Often, and 5=A Lot, Could you please tell us how often you talk with the following people in your family? If you have more than one close relative in a category, please answer the question thinking about the relative with whom you talk most frequently. How often do you talk with your _____?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N28a
b.	Daughter	1	2	3	4	5	-8	N28b
c.	Son	1	2	3	4	5	-8	N28c
d.	Mother	1	2	3	4	5	-8	N28d
e.	Grandmother	1	2	3	4	5	-8	N28e
f.	Sister	1	2	3	4	5	-8	N28f
g.	Aunt	1	2	3	4	5	-8	N28g
h.	Cousin	1	2	3	4	5	-8	N28h

13. Using the same scale, How often do you talk with each of these same people when something important and/or difficult happens in your life?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N29a
b.	Daughter	1	2	3	4	5	-8	N29b
c.	Son	1	2	3	4	5	-8	N29c
d.	Mother	1	2	3	4	5	-8	N29d
e.	Grandmother	1	2	3	4	5	-8	N29e
f.	Sister	1	2	3	4	5	-8	N29f
g.	Aunt	1	2	3	4	5	-8	N29g
h.	Cousin	1	2	3	4	5	-8	N29h

14. Before you actually got your results, How often did you discuss getting genetic testing for breast and ovarian cancer with these family members?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N30a
b.	Daughter	1	2	3	4	5	-8	N30b
c.	Son	1	2	3	4	5	-8	N30c
d.	Mother	1	2	3	4	5	-8	N30d
e.	Grandmother	1	2	3	4	5	-8	N30e
f.	Sister	1	2	3	4	5	-8	N30f
g.	Aunt	1	2	3	4	5	-8	N30g
h.	Cousin	1	2	3	4	5	-8	N30h

15. In the last six months since you received your genetic test results, How often have you discussed the results with each of them?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N31a
b.	Daughter	1	2	3	4	5	-8	N31b
c.	Son	1	2	3	4	5	-8	N31c
d.	Mother	1	2	3	4	5	-8	N31d

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
e.	Grandmother	1	2	3	4	5	-8	N31e
f.	Sister	1	2	3	4	5	-8	N31f
g.	Aunt	1	2	3	4	5	-8	N31g
h.	Cousin	1	2	3	4	5	-8	N31h

16. Overall, to what extent do your family members talk about themselves as being a family at high risk for breast or ovarian cancer?

N32

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Related Comments:

17. When you catch-up on what's going on in your family, to what extent are people's experiences with breast or ovarian cancer a topic of conversation?

N33

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Related Comments:

18. In your family, to what extent do you agree on how to manage risk for breast or ovarian cancer? N34

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Can you give me some examples of ways this comes up? _____

Have there been any disagreements about managing risk for cancer in your family? Can you tell me about that? _____

For those receiving uninformative results (No BRCA1 and BRCA2 Alterations Found AND No one in their family has a BRCA1 or BRCA2 alteration even though there is a family history of breast cancer) :

19. Even though no alteration was found for BRCA1 and BRCA2, Do you believe there is a possibility that you have another altered gene conveying an increased risk for breast and ovarian cancer?

(1) ☐ Yes (5) ☐ No

N13

20. If it becomes available, do you intend to get testing for any additional genes related to risk of breast and ovarian cancer?

(1) ☐ Yes (5) ☐ No (3) ☐ Unsure

N14

Now I want to ask you about the impact receiving results had on you. I'm going to ask you to rate the effect that getting your genetic results has had on different areas in your life. Using a scale of 1-5, 1=Very Negative Effect, 2=Somewhat Negative Effect, 3=No Effect, 4=Somewhat Positive Effect, and 5=Very Positive Effect...

21. On the whole, what effect has testing had on your life?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N15

22. Think about your everyday family life. What effect would you say getting the genetic test results has had?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N16

23. What effect has getting your results had on your work in and outside of the home?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N17

24. What effect has getting your results had on your concerns for your child's/children's future?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N19

25. Has getting these results changed the likelihood that you will have (more) children?

No/Fewer Children	No Change	More Children
1	2	3

N22

26. How has it affected your anxiety about the future?

Less Anxiety	No Change	More Anxiety
1	2	3

N18

27. Are there any OTHER areas that testing has affected?

N20

(1) ☐ Yes (5) ☐ No

27a. Please List Other Areas Affected by Genetic testing:

N20a

(more space over)

Now using a different scale of 1-5, 1=Not at All, 2=A Little, 3=Some, 4=Quite a Bit, and 5=Very Much...

28. How much has getting test results changed your health care decision(s)?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

N21

29. In general, how much has getting genetic results changed your life?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

N23

Symptoms of Strain Section

I'm going to be reading you some Symptoms Of Strain that people sometimes have. Please listen to each one carefully and tell me the answer which best reflects how much that symptom has **BOTHERED** you during the **PAST THREE MONTHS**. Please use the following scale: 1=Not at all, 2=A little, 3=Quite a bit, and 4=Extremely.

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>
1.	Suddenly scared for no reason	1	2	3	4
2.	Feeling fearful	1	2	3	4
3.	Faintness, dizziness, or weakness	1	2	3	4
4.	Nervousness or shakiness inside	1	2	3	4
5.	Heart pounding or racing	1	2	3	4
6.	Trembling	1	2	3	4
7.	Feeling tense or keyed up	1	2	3	4
8.	Headaches	1	2	3	4
9.	Spells of terror or panic	1	2	3	4
10.	Feeling restless, can't sit still	1	2	3	4

K1.

K2.

K3.

K4.

K5.

K6.

K7.

K8.

K9.

K10.

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

K26. To what extent are these current symptoms a result of getting genetic testing?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

K26

The following questions are about any counseling or psychotherapy you have received in the past, either related to cancer issues or other personal issues.

30. Have you ever seen any kind of counselor, therapist, psychologist, psychiatrist, or any other person like that for personal or emotional problems? (ASK the following probes as necessary: What type of person did you see? Why did you go? Have you ever seen someone for cancer issues? For dealing with Genetic Testing?)

Outpatient psychiatric or psychological treatment or counseling in the past 12 months:

- Exclude Educational Sessions with a Genetic Counselor
- Include treatment in outpatient and day hospital settings
- guidance or vocational counseling = No
- Axis I-type symptoms, even if not diagnosed = 3
- bereavement counseling = 4
- didactic analysis or equivalent ONLY for training/education = 8
- Family therapy ONLY to help a family member (subject did not discuss his/her own problems) = 8

Code all reasons that apply Next Page

CODE ALL REASONS THAT APPLY:

- | | | |
|---|---|------|
| a | <input type="checkbox"/> NO (Skip to Question N25) | N24a |
| b | <input type="checkbox"/> YES - Depression | N24b |
| c | <input type="checkbox"/> YES - Other Psychiatric (Axis I) | N24c |
| d | <input type="checkbox"/> YES - Interpersonal, Behavioral, Stress, Family, Developmental, etc. | N24d |
| e | <input type="checkbox"/> YES - Cancer Issues (diagnosis) | N24e |
| f | <input type="checkbox"/> YES - Genetic Testing Issues | N24f |
| g | <input type="checkbox"/> YES - Other (Specify Next page) _____ | N24g |

Specify treatment(s) and problem(s) _____

31. Are you currently seeing any kind of counselor, therapist, psychologist, psychiatrist, or any other person like that for personal or emotional problems? (ASK the following probes as necessary: What type of person are you seeing? Why are you going? Are you seeing someone for cancer issues? For dealing with Genetic Testing?)

Outpatient psychiatric or psychological treatment or counseling in the past 12 months:

- Exclude Educational Sessions with a Genetic Counselor
- Include treatment in outpatient and day hospital settings
- guidance or vocational counseling = No
- Axis I-type symptoms, even if not diagnosed = 3
- bereavement counseling = 4
- didactic analysis or equivalent ONLY for training/education = 8
- Family therapy ONLY to help a family member (subject did not discuss his/her own problems) = 8

CODE ALL REASONS THAT APPLY:

- | | | |
|---|---|------|
| a | <input type="checkbox"/> NO (Skip to Question N26) | N25a |
| b | <input type="checkbox"/> YES - Depression | N25b |
| c | <input type="checkbox"/> YES - Other Psychiatric (Axis I) | N25c |
| d | <input type="checkbox"/> YES - Interpersonal, Behavioral, Stress, Family, Developmental, etc. | N25d |
| e | <input type="checkbox"/> YES - Cancer Issues (diagnosis) | N25e |
| f | <input type="checkbox"/> YES - Genetic Testing Issues | N25f |
| g | <input type="checkbox"/> YES - Other (Specify) _____ | N25g |

Specify treatment(s) and problem(s) _____

32. Have you ever taken medication for emotional distress, depression, or anxiety?

(1) ☐ Yes (Record Meds below) (5) ☐ No (Skip to Score Hopkins)

N26

33. What medication(s) did you take? How long did you take this medication? Are you still taking this medication? Were the reasons for starting this medication related to your cancer or your risk for cancer? Were the reasons for starting this medication related to your genetic testing or receiving genetic test results?

Medications for emotional distress, depression, or anxiety:

- Include St. John's Wart
- Exclude Hormonal Treatment and other herbs

	Medication:	Code:	Duration (Months)	Currently Taking?	Related to Cancer ?	Related to Genetic Testing?	
a.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27a
b.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27b
c.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27c
d.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27d
e.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27e
f.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27f

INTERVIEWER: Go back to Score Hopkins-25 (Symptoms of Strain Section, p. 8) by adding up the numbered answers for K1-K25:

Score _____

If score = "44 or more," Complete SCID modules

If score = "43 or less," Skip SCID modules

SCID Completed

☐

WHEN FINISHED WITH INTERVIEW BE SURE TO TELL SUBJECT:

- We have a short questionnaire that we will mail in about a week with some different questions.
- We'd like to contact everyone (one last time) in about 6 months, if that is okay.
- Check Address
- Thank subject.

				-	
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WOMEN'S HEALTH STUDY

*Post-Results Questionnaire
6 Month Follow-Up*

TODAY'S DATE _____

ID _____

POST-RESULTS.2 QUESTIONNAIRE--Six Month Follow-Up

Genetic Testing Section

First, we would like to ask some questions about your reactions to receiving your genetic test results and their impact on your life.

1. How distressed were you when you received your genetic test results?

Not At All Distressed				Very Distressed
1	2	3	4	5

B69b

2. Overall, do you regret the decision to obtain your results?

Not At All				Very Much So
1	2	3	4	5

B71a

3. We are interested in the decisions women make after being notified of the results of their testing. After obtaining your results, are you now considering any of these options? Please circle only one response for each option.

		Done Before Obtaining Results	Definitely Will NOT Do	Probably Will NOT Do	Probably Will Do	Definitely Will Do	Done After Obtaining Results	Does Not Apply to Me
a.	Prophylactic Oophorectomy	0	1	2	3	4	5	-8
b.	Prophylactic Mastectomy	0	1	2	3	4	5	-8
c.	Monthly Breast Self-Exams	0	1	2	3	4	5	-8
d.	Yearly Physical Exams	0	1	2	3	4	5	-8
e.	Mammograms at least once a year	0	1	2	3	4	5	-8
f.	Encouraging my relatives to be tested	0	1	2	3	4	5	-8
g.	Discouraging my relatives from being tested	0	1	2	3	4	5	-8
h.	Telling some of my relatives what my results were	0	1	2	3	4	5	-8

B103a

B103b

B103c

B103d

B103e

B103f

B103g

B103h

4. For each of the following areas of your life, please indicate how much these decisions/plans have been affected by the results of genetic testing?

		Not at all Affected					Very Much Affected	Not Applicable	
		1	2	3	4	5		-8	
a.	Decisions about having children	1	2	3	4	5		-8	B35c
b.	Decisions about forms of birth control	1	2	3	4	5		-8	B36c
c.	Decisions about which steps to take to prevent breast cancer	1	2	3	4	5		-8	B37c
d.	Decisions about work and career	1	2	3	4	5		-8	B38c
e.	Decisions about savings and financial planning	1	2	3	4	5		-8	B39c
f.	Plans for your future	1	2	3	4	5		-8	B40c
g.	Plans for your daughter's future	1	2	3	4	5		-8	B42c

5. [Now that you have received genetic results and have more information about your risk of developing breast or ovarian cancer,] After receiving your genetic test results, how likely do you think you are to develop breast or ovarian cancer (or develop breast or ovarian cancer again), compared to **the average woman**? (Please circle one) B7a

Much Less Likely			Much More Likely		
1	2	3	4	5	

6. After receiving your genetic test results, how likely do you think you are to develop breast or ovarian cancer (or develop breast or ovarian cancer again), compared to **the women in your family**? (Please circle one) B8a

Much Less Likely			Much More Likely		
1	2	3	4	5	

7. Overall, what do you believe your risk to be of developing breast or ovarian cancer (or developing breast or ovarian cancer again) **in the near future**? B6

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

8. Overall, what do you believe your risk to be of developing breast or ovarian cancer (or developing breast or ovarian cancer again) **at some point in your lifetime?** B7

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

9. Now, we would like to ask you some questions about worries you may or may not experience.

		<div>Not At All</div> <div>All The Time</div>					
a.	How often do you worry about developing breast cancer or developing breast cancer again?	1	2	3	4	5	B27
b.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28
c.	How often do you worry about developing ovarian cancer or developing ovarian cancer again?	1	2	3	4	5	B110
d.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B111
e.	How often do you worry about your relatives developing breast or ovarian cancer?	1	2	3	4	5	B106
f.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B107
g.	How often do you worry about your relatives having an altered gene associated with risk for breast and ovarian cancer?	1	2	3	4	5	B108
h.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B109

Coping Section

1. How confident are you that **you** are coping effectively after getting your genetic test results?

Not At All Confident						Very Confident
1	2	3	4	5	6	7

B48e

2. How confident are you that **your family members** are coping effectively with the results of your genetic testing?

Not At All Confident						Very Confident
1	2	3	4	5	6	7

B48f

3. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of genetic test results. For each of the statements below, indicate the degree to which your life has been affected positively by finding out your results.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j
k.	Appreciating each day.	1	2	3	4	5	6	L6k
l.	Having compassion for others.	1	2	3	4	5	6	L6l
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n
o.	Putting effort into my relationships.	1	2	3	4	5	6	L6o
p.	I have a stronger religious faith.	1	2	3	4	5	6	L6p
q.	I discovered that I'm stronger than I thought I was.	1	2	3	4	5	6	L6q
r.	I learned a great deal about how wonderful people are.	1	2	3	4	5	6	L6r
s.	I developed new interests.	1	2	3	4	5	6	L6s
t.	I accept needing others.	1	2	3	4	5	6	L6t
u.	I established a new path for my life.	1	2	3	4	5	6	L6u

5. Below is a list of comments made by people after they have received their genetic test results. When you read each comment, think about your thoughts and feelings toward the test results. Please indicate how often each of the comments was true for you since you received your test results, with the choices of *Not at All*, *Rarely*, *Sometimes*, and *Often*.

“IT” in the following questions refers to “RECEIVING YOUR TEST RESULTS”)		Not at All	Rarely	Sometimes	Often	
a.	I thought about it when I didn't mean to.	0	1	3	5	B116a
b.	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	3	5	B116b
c.	I tried to remove it from memory.	0	1	3	5	B116c
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.	0	1	3	5	B116d
e.	I had waves of strong feelings about it.	0	1	3	5	B116e
f.	I had dreams about it.	0	1	3	5	B116f
g.	I stayed away from reminders of it.	0	1	3	5	B116g

"T" in the following questions refers to
"RECEIVING YOUR TEST RESULTS")

		Not at All	Rarely	Sometimes	Often	
h.	I felt as if it hadn't happened or it wasn't real.	0	1	3	5	B116h
i.	I tried not to talk about it.	0	1	3	5	B116i
j.	Pictures about it popped into my mind.	0	1	3	5	B116j
k.	Other things kept making me think about it.	0	1	3	5	B116k
l.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	3	5	B116l
m.	I tried not to think about it.	0	1	3	5	B116m
n.	Any reminder brought back feelings about it.	0	1	3	5	B116n
o.	My feelings about it were kind of numb.	0	1	3	5	B116o

Mood Section

1. In the past 6 months, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?

I12

(1) ☐ Yes (5) ☐ No (Skip to Health Section, Next Page)

- 1a. During this period, did your work or relationships suffer?
 (1) ☐ Yes (5) ☐ No

I12a

- 1b. During this period, did you get counseling or psychotherapy?
 (1) ☐ Yes (5) ☐ No

I12b

- 1c. During this period, did you get medication for this condition?
 (1) ☐ Yes (5) ☐ No

I12c

Health Section

1. How often do you usually get a mammogram? B32a
- 1 ☐ Never (I have never had a mammogram).
 2 ☐ Less than Once a Year
 3 ☐ Once a Year
 4 ☐ More than Once a Year
 -8 ☐ Does Not Apply because of surgery
2. How often do you perform self-examination of your breasts? B33a
- 1 ☐ Never or rarely
 2 ☐ Less than Once a Month
 3 ☐ Monthly
 4 ☐ More than Once a Month
 -8 ☐ Does Not Apply because of surgery
3. How often do you get CA-125 screening for ovarian cancer? B33b
- 1 ☐ Never (I have never had a CA-125 screening).
 2 ☐ Less than Once a Year
 3 ☐ Once a Year
 4 ☐ More than Once a Year
 -8 ☐ Does Not Apply because of surgery
4. How often do you get ultrasound screening for ovarian cancer? B33c
- 1 ☐ Never (I have never had an ovarian ultrasound for cancer screening).
 2 ☐ Less than Once a Year
 3 ☐ Once a Year
 4 ☐ More than Once a Year
 -8 ☐ Does Not Apply because of surgery
5. Has knowing your genetic results affected your **motivation** to perform breast self examination as frequently as needed? B34d
- | Decreased Motivation | 2 | No Effect | 4 | Increased Motivation | Does Not Apply because of surgery |
|----------------------|---|-----------|---|----------------------|-----------------------------------|
| 1 | | 3 | | 5 | -8 |
6. Has knowing your genetic results affected your **confidence** that you will perform breast self examination as frequently as needed? B34e
- | Decreased Confidence | 2 | No Effect | 4 | Increased Confidence | Does Not Apply because of surgery |
|----------------------|---|-----------|---|----------------------|-----------------------------------|
| 1 | | 3 | | 5 | -8 |

7. Has knowing your genetic results affected your **confidence** that you will perform breast self examination as **carefully and competently** as needed?

Decreased Confidence		No Effect		Increased Confidence	Does Not Apply because of surgery
1	2	3	4	5	-8

B34f

8. How confident are you that you would be able to detect a change in your breasts using breast self examination?

Not At All						Very Much So	Does Not Apply because of surgery
1	2	3	4	5	6	7	-8

B34c

9. In general, would you say your health is:

1 ☐ Excellent 2 ☐ Very Good 3 ☐ Good 4 ☐ Fair 5 ☐ Poor

I1

10. Compared to one year ago, how would you rate your health in general now? (Please Check One) I2

- 1 ☐ Much better now than one year ago
 2 ☐ Somewhat better now than one year ago
 3 ☐ About the same as one year ago
 4 ☐ Somewhat worse now than one year ago
 5 ☐ Much worse than one year ago

11. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **emotional** problems (such as feeling depressed or anxious)?

		Yes	No
a.	Cut down the amount of time you spent on work or other activities.	1	5
b.	Accomplished less than you would like.	1	5
c.	Didn't do work or other activities as carefully as usual.	1	5

I5a

I5b

I5c

12. **During the past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

I6

1 ☐ Not at all 2 ☐ Slightly 3 ☐ Moderately 4 ☐ Quite a bit 5 ☐ Extremely

13. How much bodily pain have you had **during the past 4 weeks**?

I7

1 ☐ None 2 ☐ Very Mild 3 ☐ Mild 4 ☐ Moderate 5 ☐ Severe 6 ☐ Very Severe

14. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

I8

1 ☐ Not at all 2 ☐ Slightly 3 ☐ Moderately 4 ☐ Quite a bit 5 ☐ Extremely

15. These questions are about how you feel and how things have been with you during the past **4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks**: Please mark the appropriate box to indicate your response.

		<i>All of the time</i>	<i>Most of the time</i>	<i>A good bit of the time</i>	<i>Some of the time</i>	<i>A little of the time</i>	<i>None of the time</i>
a.	Did you feel full of pep?	1	2	3	4	5	6
b.	Have you been a very nervous person?	1	2	3	4	5	6
c.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d.	Have you felt calm and peaceful?	1	2	3	4	5	6
e.	Did you have a lot of energy?	1	2	3	4	5	6
f.	Have you felt downhearted and blue?	1	2	3	4	5	6
g.	Did you feel worn out?	1	2	3	4	5	6
h.	Have you been a happy person?	1	2	3	4	5	6
i.	Did you feel tired?	1	2	3	4	5	6

I9a

I9b

I9c

I9d

I9e

I9f

I9i

I9g

I9h

16. **During the past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

I10

- 1 ☐ All of the time
 2 ☐ Most of the time
 3 ☐ Some of the time
 4 ☐ A little of the time
 5 ☐ None of the time

17. How **TRUE** or **FALSE** is each of the following statements for you?

		<i>Definitely True</i>	<i>Mostly True</i>	<i>Don't Know</i>	<i>Mostly False</i>	<i>Definitely False</i>
a.	I seem to get sick a little easier than other people.	1	2	3	4	5
b.	I am as healthy as anybody I know.	1	2	3	4	5
c.	I expect my health to get worse.	1	2	3	4	5
d.	My health is excellent.	1	2	3	4	5

I11a

I11b

I11c

I11d

LIFE EVENTS SECTION

1. Have any of the following events happened to you in the past six months? D1(a-m)
(Check All That Apply)
- | | |
|---|---|
| <p>a. <input type="checkbox"/> You retired, were fired, or laid off from work.</p> <p>b. <input type="checkbox"/> You were unemployed and looking for work.</p> <p>c. <input type="checkbox"/> Your spouse retired, was fired, or laid off from work.</p> <p>d. <input type="checkbox"/> Your spouse was unemployed and looking for work.</p> <p>e. <input type="checkbox"/> You had problems with the police or court.</p> <p>f. <input type="checkbox"/> You got into serious financial difficulties.</p> | <p>g. <input type="checkbox"/> A close family member was seriously ill or injured.</p> <p>h. <input type="checkbox"/> You had a marital separation or divorce.</p> <p>i. <input type="checkbox"/> You had serious troubles with relatives or close friends.</p> <p>j. <input type="checkbox"/> Your spouse had troubles or difficulties with relatives or close friends.</p> <p>k. <input type="checkbox"/> A close family member died.</p> <p>l. <input type="checkbox"/> A close friend or relative died.</p> <p>m. <input type="checkbox"/> You were seriously ill or injured.</p> |
|---|---|

This last section deals with your views of cancer prevention and treatment.

1. To what extent do you agree with the following statements?

		Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	
a.	In the next year, there will be dramatic breakthroughs in the <u>prevention</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7a
b.	In the next year, there will be dramatic breakthroughs in the <u>treatment</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7b
c.	In the next year, the length of <u>survival</u> after diagnosis of breast cancer will increase.	1	2	3	4	5	N7c
d.	In the next year, the length of <u>survival</u> after diagnosis of ovarian cancer will increase.	1	2	3	4	5	N7d

		Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	
e.	In the next 5 years, there will be dramatic breakthroughs in the <u>prevention</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7e
f.	In the next 5 years, there will be dramatic breakthroughs in the <u>treatment</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7f
g.	In the next five years, the length of <u>survival</u> after diagnosis of breast cancer will increase.	1	2	3	4	5	N7g
h.	In the next five years, the length of <u>survival</u> after diagnosis of ovarian cancer will increase.	1	2	3	4	5	N7h
i.	In the future, all women will routinely receive genetic testing for risk of breast and ovarian cancer.	1	2	3	4	5	N7i

Thank You Very Much For Your Participation!

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WOMEN'S HEALTH STUDY

Post-Results Questionnaire #3
12 Month Follow-Up

TODAY'S DATE _____

ID _____

POST-RESULTS.3--12 Month Follow-Up

First of all, we would like to acknowledge that we are asking many of the same questions that we've asked before. This way we can better understand how your reactions have changed or have stayed the same over time.

Genetic Testing

1. How distressed were you when you received your genetic test results?

Not At All Distressed		Very Distressed		
1	2	3	4	5

B69b

2. Overall, do you regret the decision to obtain your results?

Not At All		Very Much So		
1	2	3	4	5

B71a

3. With your genetic test results, Are you now considering any of the following options?
Please circle only one response for each option.

		Done Before Obtaining Results	Definitely Will NOT Do	Probably Will NOT Do	Probably Will Do	Definitely Will Do	Done After Obtaining Results	Does Not Apply to Me
a.	Prophylactic Oophorectomy (ovaries removed)	0	1	2	3	4	5	-8
b.	Prophylactic Mastectomy	0	1	2	3	4	5	-8
c.	Monthly Breast Self-Exams	0	1	2	3	4	5	-8
d.	Yearly Physical Exams	0	1	2	3	4	5	-8
e.	Mammograms at least once a year	0	1	2	3	4	5	-8
f.	Encouraging my relatives to be tested	0	1	2	3	4	5	-8
g.	Discouraging my relatives from being tested	0	1	2	3	4	5	-8
h.	Telling some of my relatives what my results were	0	1	2	3	4	5	-8

B103a

B103b

B103c

B103d

B103e

B103f

B103g

B103h

4. For each of the following areas of your life, please indicate how much these decisions/plans have been affected by the results of genetic testing?

		<i>Not at all Affected</i>					<i>Very Much Affected</i>	<i>Not Applicable</i>	
		1	2	3	4	5			
a.	Decisions about having children	1	2	3	4	5		-8	B35c
b.	Decisions about forms of birth control	1	2	3	4	5		-8	B36c
c.	Decisions about which steps to take to prevent breast cancer	1	2	3	4	5		-8	B37c
d.	Decisions about work and career	1	2	3	4	5		-8	B38c
e.	Decisions about savings and financial planning	1	2	3	4	5		-8	B39c
f.	Plans for your future	1	2	3	4	5		-8	B40c
g.	Plans for your daughter's future	1	2	3	4	5		-8	B42c

5. On the whole, what effect has testing had on your life?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	
1	2	3	4	5	N15

6. Think about your everyday family life. What effect would you say getting the genetic test results has had?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	
1	2	3	4	5	N16

7. What effect has getting your results had on your work in and outside of the home?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	
1	2	3	4	5	N17

8. What effect has getting your results had on your concerns for your child's/children's future?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N19

9. Has getting these results changed the likelihood that you will have (more) children?

Yes, Will Have Fewer Children	No Change	Yes, Will Have More Children
1	2	3

N22

10. How has getting genetic testing affected your anxiety about the future?

Less Anxiety	No Change	More Anxiety
1	2	3

N18

11. Are there any OTHER areas of your life that testing has affected?

N20

(1) ☐ Yes (5) ☐ No

- 11a. Please List Other Areas of your life Affected by Genetic testing:

N20a

12. How much has getting test results changed your health care decision(s)?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

N21

12a. If applicable, How have your health care decisions changed?

13. In general, how much has getting genetic results changed your life?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

N23

13a. If applicable, How has your life changed?

14. Now, we would like to ask you some questions about worries you may or may not experience.

		<div>Not At All</div> <div>All The Time</div>					
a.	How often do you worry about developing breast cancer or developing breast cancer again?	1	2	3	4	5	B27
b.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28
c.	How often do you worry about developing ovarian cancer or developing ovarian cancer again?	1	2	3	4	5	B110
d.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B111
e.	How often do you worry about your relatives developing breast or ovarian cancer?	1	2	3	4	5	B106
f.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B107
g.	How often do you worry about your relatives having an altered gene associated with risk for breast and ovarian cancer?	1	2	3	4	5	B108
h.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B109

Coping Section

1. How confident are you that **you** are coping effectively after getting your genetic test results?

Not At All Confident						Very Confident
1	2	3	4	5	6	7

B48e

2. How confident are you that **your family members** are coping effectively with the results of your genetic testing?

Not At All Confident						Very Confident
1	2	3	4	5	6	7

B48f

3. Below is a list of comments made by people after they have received their genetic test results. When you read each comment, think about your thoughts and feelings toward the test results. Please indicate how often each of the comments has been true for you since you received your test results, with the choices of *Not at All*, *Rarely*, *Sometimes*, and *Often*.

“II” in the following questions refers to
“RECEIVING YOUR TEST RESULTS”)

		Not at All	Rarely	Sometimes	Often
a.	I thought about it when I didn't mean to.	0	1	3	5
b.	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	3	5
c.	I tried to remove it from memory.	0	1	3	5
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.	0	1	3	5
e.	I had waves of strong feelings about it.	0	1	3	5
f.	I had dreams about it.	0	1	3	5
g.	I stayed away from reminders of it.	0	1	3	5
h.	I felt as if it hadn't happened or it wasn't real.	0	1	3	5
i.	I tried not to talk about it.	0	1	3	5
j.	Pictures about it popped into my mind.	0	1	3	5

B116a

B116b

B116c

B116d

B116e

B116f

B116g

B116h

B116i

B116j

"IT" in the following questions refers to
"RECEIVING YOUR TEST RESULTS")

		Not at All	Rarely	Sometimes	Often	
k.	Other things kept making me think about it.	0	1	3	5	B116k
l.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	3	5	B116l
m.	I tried not to think about it.	0	1	3	5	B116m
n.	Any reminder brought back feelings about it.	0	1	3	5	B116n
o.	My feelings about it were kind of numb.	0	1	3	5	B116o

Family Events

We would like to ask you if there were any recent events in your family related to cancer or risk for cancer.

1. To your knowledge, have any of your family members received genetic test results **in the past 6 months**? What is their relationship to you? Do you know if a mutation was found? Positive or Negative?

(1) ☐ Yes (5) ☐ No (Skip to Next Question)

Total # of Family Members who Received Results: _____

N8t

	Relationship to You:	Positive Mutation Found	Negative No Mutation Found	Don't Know	
a.		1	0	-9	N8a
b.		1	0	-9	N8b
c.		1	0	-9	N8c

2. Have any of your family members declined receiving test results **in the past 6 months**?

(1) ☐ Yes (5) ☐ No (Skip to Next Question)

Total # of Family Members who Declined Results: _____

N9t

	Relationship to You:	
a.		N9a
b.		N9b
c.		N9c

3. Have any family members received a new diagnosis of cancer **in the past 6 months?**

(1) ☐ Yes (5) ☐ No (Skip to Next Question)

Total # of Family Members who had a New Diagnosis of cancer : _____

N10t

	Relationship to You:	
a.		N10a
b.		N10b
c.		N10c

4. Have any family members had prophylactic surgery **in the past 6 months?**

(1) ☐ Yes (5) ☐ No (Skip to Next Question)

Total # of Family Members who had Prophylactic Surgery: _____

N11

	Relationship to You:	Prophylactic Procedure:	
a.			N11a
b.			N11b
c.			N11c

5. Have any family members had any other things happen related to cancer or risk of cancer **in the past 6 months?** [such as treatment, surgery, or death?]

(1) ☐ Yes (5) ☐ No (Skip to Next Question)

Total # Family Members with a Cancer Related Event: _____

N12

	Relationship to You:	Event related to cancer:	
a.			N12a
b.			N12b
c.			N12c

6. In the last six months, How often have you discussed your genetic results with each of the following family members?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N31a
b.	Daughter	1	2	3	4	5	-8	N31b
c.	Son	1	2	3	4	5	-8	N31c

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
d.	Mother	1	2	3	4	5	-8	N31d
e.	Grandmother	1	2	3	4	5	-8	N31e
f.	Sister	1	2	3	4	5	-8	N31f
g.	Aunt	1	2	3	4	5	-8	N31g
h.	Cousin	1	2	3	4	5	-8	N31h

Health Section

1. How often do you usually get a mammogram? B32a
- 1 ☐ Never (I have never had a mammogram).
- 2 ☐ Less than Once a Year
- 3 ☐ Once a Year
- 4 ☐ More than Once a Year
- 8 ☐ Does Not Apply because of surgery

2. How often do you perform self-examination of your breasts? B33a
- 1 ☐ Never or rarely
- 2 ☐ Less than Once a Month
- 3 ☐ Monthly
- 4 ☐ More than Once a Month
- 8 ☐ Does Not Apply because of surgery

3. How often do you get CA-125 screening for ovarian cancer? B33b
- 1 ☐ Never (I have never had a CA-125 screening).
- 2 ☐ Less than Once a Year
- 3 ☐ Once a Year
- 4 ☐ More than Once a Year
- 8 ☐ Does Not Apply because of surgery

4. How often do you get ultrasound screening for ovarian cancer? B33c
- 1 ☐ Never (I have never had an ovarian ultrasound for cancer screening).
- 2 ☐ Less than Once a Year
- 3 ☐ Once a Year
- 4 ☐ More than Once a Year
- 8 ☐ Does Not Apply because of surgery

5. Has knowing your genetic results affected your **motivation** to perform breast self examination as frequently as needed?

Decreased Motivation	No Effect		Increased Motivation		Does Not Apply because of surgery
1	2	3	4	5	-8

B34d

6. Has knowing your genetic results affected your **confidence** that you will perform breast self examination as **frequently** as needed?

Decreased Confidence		No Effect		Increased Confidence		Does Not Apply because of surgery
1	2	3	4	5	-8	

B34e

7. Has knowing your genetic results affected your **confidence** that you will perform breast self examination as **carefully and competently** as needed?

Decreased Confidence		No Effect		Increased Confidence		Does Not Apply because of surgery
1	2	3	4	5	-8	

B34f

Symptoms of Strain Section

Listed below are some symptoms of strain that people sometimes have. Please read Each One Carefully And Circle The Answer Which Best Reflects How Much That Symptom Has **BOTHERED** you during the **PAST THREE MONTHS**. Please use the following scale: 1=Not at all, 2=A little, 3=Quite a bit, and 4=Extremely.

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>
1.	Suddenly scared for no reason	1	2	3	4
2.	Feeling fearful	1	2	3	4
3.	Faintness, dizziness, or weakness	1	2	3	4
4.	Nervousness or shakiness inside	1	2	3	4
5.	Heart pounding or racing	1	2	3	4
6.	Trembling	1	2	3	4
7.	Feeling tense or keyed up	1	2	3	4
8.	Headaches	1	2	3	4
9.	Spells of terror or panic	1	2	3	4
10.	Feeling restless, can't sit still	1	2	3	4
11.	Feeling low in energy--slowed down	1	2	3	4
12.	Blaming yourself for things	1	2	3	4
13.	Crying easily	1	2	3	4
14.	Loss of sexual interest or pleasure	1	2	3	4

K1.

K2.

K3.

K4.

K5.

K6.

K7.

K8.

K9.

K10.

K11.

K12.

K13.

K14.

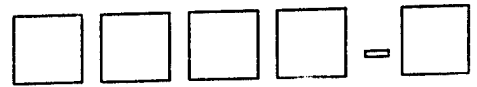
		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

26. To what extent are these current symptoms a result of getting genetic testing?

Not At All	A Little	Some	Quite a Bit	Very Much	
1	2	3	4	5	K26

Your Participation has been very much appreciated. Your contribution to the study of genetic testing for breast and ovarian cancer has been great. This is the last questionnaire for our study. A sincere thank you for hanging in with us over the past few years!

-Women's Health Study Staff



WOMEN'S HEALTH STUDY

Spouse/Partner Questionnaire

Today's Date _____

A-ID _____

SPOP

BACKGROUND DATA SECTION

1. Date of Birth _____ Month _____ Day _____ Year **A1.**
2. Ethnic Background: White ☐ 1 Black ☐ 4 **A2.**
Hispanic ☐ 2 Asian ☐ 5
Native American ☐ 3 Other ☐ 6
3. Religion: Catholic ☐ 1 Protestant ☐ 4 **A3.**
Jewish ☐ 2 Buddhist ☐ 5
Muslim ☐ 3 Other ☐ 6
None ☐ 7
- 3a. How often do you attend religious services? **A3a.**
☐ 1 Less Than Once a Month ☐ 5 A Few Times A Month or More
- 3b. How important are religious and spiritual beliefs in your life? **A3b.**
Not at All 1 2 3 4 5 Very Important
4. Are you currently working for pay outside the home? Yes ☐ 1 No ☐ 5 **A7.**
5. If yes, about how many hours per week are you working for pay? **A8.**
Less than 10 10-20 21-30 31-40 41 or more
☐ ☐ ☐ ☐ ☐
(1) (2) (3) (4) (5)
6. What is the highest level of education you have completed? (Check one) **A9.**
1 ☐ Less than 9th grade 5 ☐ Completed college
2 ☐ Dropped out of high school 6 ☐ Some graduate or professional training
3 ☐ Completed high school 7 ☐ Completed graduate or professional training
4 ☐ Some college

The following two questions are optional, but we hope that you will provide this information.
Please check the appropriate box. (Check one)

7. What is your household's total income? (Check one) **A10.**
(1) ☐ Less than \$10,000 (4) ☐ \$30,000 to \$39,999 (7) ☐ \$60,000 to \$69,999
(2) ☐ \$10,000 to \$19,999 (5) ☐ \$40,000 to \$49,999 (8) ☐ Greater than \$69,999
(3) ☐ \$20,000 to \$29,999 (6) ☐ \$50,000 to \$59,999
8. How many people (adults and children) does this income support? _____ **A11.**

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

HEALTH SECTION

The following questions concern your wife/partner's risk of developing breast cancer again and of her having the altered gene which has been found to be associated with increased risk for breast cancer. As you may know, breast cancer runs in certain families. In some of these families, persons who develop cancer have an altered version of a gene, BRCA1. Some family members will inherit the gene and others will not.

		<i>Not At All</i>			<i>All The Time</i>	
1.	How often do you worry about your wife/partner again developing breast cancer?	1	2	3	4	5
2.	To what extent do these worries interfere with your every day life?	1	2	3	4	5
3.	How often do you worry about your wife/partner having the altered gene associated with risk for breast cancer?	1	2	3	4	5
4.	To what extent do worries about your wife/partner having this altered gene interfere with your every day life?	1	2	3	4	5
5.	How often do you worry about developing cancer yourself?	1	2	3	4	5

B27.

B28.

B29.

B30.

B31.

6. How likely do you think your wife/partner is to develop breast cancer again in the near future? **B9.**
(Please circle one).

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

7. Overall, what do you believe your wife/partner's risk is of developing breast cancer again at some point in her lifetime? **B10.**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

8. Overall, what do you believe your wife/partner's risk is of developing some other cancer unrelated to breast cancer at some point in her lifetime? **B14.**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

9. How often does your wife/partner express concern and seek support from you about the risk of breast cancer to herself and women in her family? **B49.**

Never	Rarely	Sometimes	Often
1	2	3	4

10. How much of a burden is this on you?

B50.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

11. How often do you discuss genetic testing for breast cancer with your wife/partner?

B51.

Never	Rarely	Sometimes	Often
1	2	3	4

12. When you have these discussions, who generally initiates them?

B52.

You	Your Wife/partner	Equally
1	2	3

13. How satisfied are you with these discussions?

B53.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

14. How often do you and your wife/partner get into a disagreement or conflict over the issue of her getting genetic testing for the risk of breast cancer?

B54.

Never	Rarely	Sometimes	Often
1	2	3	4

15. Do you think it is beneficial to have genetic testing for risk of breast cancer available to women?

B55.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

16. Do you want your wife/partner to get genetic testing for risk of breast cancer?

B56.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17. Overall, how much do you want your opinion to be taken into account in your wife/partner's decision **whether to be tested** for the breast cancer gene?

B57.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

18. Overall, how much do you want your opinion to be taken into account in your wife/partner's decisions **about what to do about her risk** for breast cancer?

B58.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

19. Overall, how important is your opinion in your wife/partner's decision whether to be tested for the altered gene carrying susceptibility to breast cancer?

B59.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 19a. Do you believe your wife has the altered gene that increases the risk of breast cancer?

B60.

(1) ☐ Yes (5) ☐ No

- 19b. How confident are you in this belief?

Not At All Confident						Very Confident
1	2	3	4	5	6	7

B61.

20. Have you attended individual, family or group sessions to become informed about your wife/partner's risk for breast cancer and what can be done?

B62.

(1) ☐ Yes (5) ☐ No

21. How much contact have you had with medical personnel concerning her risk of cancer?

B63.

Very Little 1 2 3 4 5 6 A Lot 7

- 22a. Overall, do you feel you are adequately informed concerning your wife/partner's risk for cancer and what can be done about it? **B43a.**
- Not at All 1 2 3 4 5 6 7 Very Much
- 22b. Do you feel you are adequately informed about your wife/partner's risk for developing breast cancer **again**? **B43b.**
- Not at All 1 2 3 4 5 6 7 Very Much
- 22c. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer? **B44.**
- Not at All 1 2 3 4 5 6 7 Very Much
- 22d. Do you feel you are adequately informed about what your wife/partner could do personally to reduce her risk of breast cancer if she had the altered BRCA1 gene? **B45.**
- Not at All 1 2 3 4 5 6 7 Very Much
- 22e. Do you feel you are adequately informed about the benefits and drawbacks of options available to women who have the altered BRCA1 gene? **B46.**
- Not at All 1 2 3 4 5 6 7 Very Much
- 22f. Do you feel you are adequately informed about what it would mean for your children if your wife/partner had the altered BRCA1 gene? ☐ **Check here if you do not have children.** **B47.**
- (-8)
- Not at All 1 2 3 4 5 6 7 Very Much **C-22f.**
23. How confident are you that your wife/partner:
- 23a. Will make the best decision about whether to be tested for BRCA1, the altered gene associated with risk of breast cancer? **B48a.**
- Not at All 1 2 3 4 5 6 7 Very Much
- 23b. Would cope effectively with the finding that she had the altered BRCA1 gene? **B48b.**
- Not at All 1 2 3 4 5 6 7 Very Much

23. (continued) How confident are you that your wife/partner:

23c. Would make the best decision concerning her options if she were found to have the altered BRCA1 gene? B48c.

Not at All 2 3 4 5 6 7 Very Much

23d. Would be able to follow through with her decisions and cope effectively over the long haul if she were found to have the altered BRCA1 gene? B48d.

Not at All 2 3 4 5 6 7 Very Much

24. Please indicate the extent to which you agree or disagree with the following statements using the 1 (strongly disagree) to 5 (strongly agree) scale. Please try to provide your opinion for all of these questions. However, if you feel you simply do not know enough to have an opinion, check the "I don't know" box.

		Strongly Disagree			Strongly Agree		I Don't Know	
		1	2	3	4	5	9	
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9	B20a.
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	B20c.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.
g.	If a woman were found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5	9	B20m.
h.	Once a woman has had effective treatment for breast cancer, she will not get it again.	1	2	3	4	5	9	B20n.
i.	A mastectomy totally eliminates a woman's risk for breast cancer.	1	2	3	4	5	9	B20o.
j.	All women who have the altered version of the BRCA1 gene will get breast cancer.	1	2	3	4	5	9	B20p.
k.	Most of the breast cancer in the United States is due to altered versions of the BRCA1 gene.	1	2	3	4	5	9	B20q.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>
l.	The next decade is going to bring major advances in the detection and treatment of breast cancer.	1	2	3	4	5	9
m.	Over the next decade, medical breakthroughs are going to make breast cancer much less of a threat to women's health.	1	2	3	4	5	9

B20r.

B20s.

25. If your wife/partner were to take the test and find that she **did not** have the altered version of the BRCA1 gene which is associated with high risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
a.	I would feel wonderful.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would feel relieved.	1	2	3	4	5
d.	I would not believe the results.	1	2	3	4	5
e.	I would fall apart emotionally.	1	2	3	4	5
f.	I would feel guilty.	1	2	3	4	5
g.	I would still feel anxious.	1	2	3	4	5
h.	I would feel angry.	1	2	3	4	5
i.	I would feel prepared for the future.	1	2	3	4	5
j.	I would feel I had done all I needed to do.	1	2	3	4	5
k.	I would not feel very differently.	1	2	3	4	5

B18a.

B18b.

B18c.

B18d.

B18e.

B18f.

B18g.

B18h.

B18i.

B18j.

B18k.

26. If your wife/partner were to take the test and find out that she **had** the altered version of the BRCA1 gene for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
a.	I would feel relieved about being more certain.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would not believe the results.	1	2	3	4	5
d.	I would feel guilty.	1	2	3	4	5
e.	I would feel depressed.	1	2	3	4	5

B19a.

B19b.

B19c.

B19d.

B19e.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
		1	2	3	4	5
f.	I would feel worried about the future.	1	2	3	4	5
g.	I would fall apart emotionally.	1	2	3	4	5
h.	I would feel anxious.	1	2	3	4	5
i.	I would feel angry.	1	2	3	4	5
j.	I would not feel very differently.	1	2	3	4	5
k.	I would want my daughters to be tested as soon as possible.	1	2	3	4	5

B19f.

B19g.

B19h.

B19i.

B19j.

B19k.

27. The following questions concern your involvement in your wife/partner's health care:

		<i>Not at All</i>			<i>Very Often</i>	
		1	2	3	4	5
a.	To what extent do you go with your wife/partner to her appointments with doctors?	1	2	3	4	5
b.	To what extent do you talk with your wife/partner's doctor or other medical personnel about her risk of cancer?	1	2	3	4	5
c.	To what extent do you keep track of what your wife/partner needs to do about her risk of cancer?	1	2	3	4	5
d.	To what extent do you change your activities to look after your wife/partner?	1	2	3	4	5

H35a.

H35b.

H35c.

H35d.

28. If my wife/partner were tested and found to have the altered BRCA1 gene carrying increased risk of breast cancer, I would want her to manage her risk by relying:

- a. Being extra careful about breast self-examination and regular medical examinations.

B64a.

Not at All						Very Much So
1	2	3	4	5	6	7

- b. Getting preventive surgery.

B64b.

Not at All						Very Much So
1	2	3	4	5	6	7

29. I do not believe it would be my place to tell my wife/partner my opinion about what she should do about her risk of breast cancer.

B65.

Strongly Disagree						Strongly Agree
1	2	3	4	5	6	7

RELATIONSHIPS

1. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.

(1) ☐ Yes (5) ☐ No

2. Can you share your most private feelings with your wife/partner without holding back? C21a.

(1) ☐ Yes (5) ☐ No

3. Is there anyone besides your wife/partner with whom you can share your most private feelings without holding back? C21b.

(1) ☐ Yes (5) ☐ No

4. Have any of the events listed below happened to you in the past six months? D1 (a-n)
(Check All That Apply)

- | | |
|---|---|
| <p>a. <input type="checkbox"/> You retired or were fired or laid off from work.</p> <p>b. <input type="checkbox"/> You were unemployed and looking for work.</p> <p>c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work.</p> <p>d. <input type="checkbox"/> Your spouse was unemployed and looking for work.</p> <p>e. <input type="checkbox"/> You had problems with the police or court.</p> <p>f. <input type="checkbox"/> You got into serious financial difficulties.</p> | <p>g. <input type="checkbox"/> A close family member was seriously ill or injured.</p> <p>h. <input type="checkbox"/> You had a marital separation or divorce.</p> <p>i. <input type="checkbox"/> You had serious troubles with relatives or close friends.</p> <p>j. <input type="checkbox"/> Your spouse had troubles with relatives or close friends.</p> <p>k. <input type="checkbox"/> A close family member died.</p> <p>l. <input type="checkbox"/> A close friend or relative died.</p> <p>m. <input type="checkbox"/> You were seriously ill or injured.</p> |
|---|---|

MARRIAGE SECTION

Most people have disagreements in their relationships. Please indicate, using check marks the extent of agreement or disagreement experienced between you and your wife/partner on the following issues **DURING THE PAST MONTH**.

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occa- sionally Disagree</i>	<i>Fre- quently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>
1.	Handling family finances	1	2	3	4	5	6
2.	Matters of recreation	1	2	3	4	5	6
3.	Religious matters	1	2	3	4	5	6
4.	Demonstration of affection	1	2	3	4	5	6
5.	Friends	1	2	3	4	5	6
6.	Sex relations	1	2	3	4	5	6
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6
8.	Philosophy of life	1	2	3	4	5	6
9.	Ways of dealing with parents or in-laws	1	2	3	4	5	6
10.	Aims, goals, and things believed important	1	2	3	4	5	6
11.	Amount of time spent together	1	2	3	4	5	6
12.	Making major decisions	1	2	3	4	5	6
13.	Household tasks	1	2	3	4	5	6
14.	Leisure time interests and activities	1	2	3	4	5	6
15.	Career decisions	1	2	3	4	5	6

H1.

H2.

H3.

H4.

H5.

H6.

H7.

H8.

H9.

H10.

H11.

H12.

H13.

H14.

H15.

		<i>All of the Time</i>	<i>Most of the Time</i>	<i>More Often than Most</i>	<i>Occa- sionally</i>	<i>Rarely</i>	<i>Never</i>
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6
17.	How often do you or your wife/partner leave the house after a fight?	1	2	3	4	5	6
18.	In general, how often do you think that things between you and your wife/partner are going well?	1	2	3	4	5	6
19.	Do you confide in your wife/partner?	1	2	3	4	5	6
20.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6
21.	How often do you and your wife/partner quarrel?	1	2	3	4	5	6
22.	How often do you and your wife/partner "get on each other's nerves?"	1	2	3	4	5	6

H16.

H17.

H18.

H19.

H20.

H21.

H22.

		<i>Every Day</i>	<i>Almost Every Day</i>	<i>Occa- sionally</i>	<i>Rarely</i>	<i>Never</i>
23.	Do you kiss your wife/partner?	1	2	3	4	5

H23.

		<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>
24.	Do you and your wife/partner engage in outside interests together?	1	2	3	4	5

H24.

How often would you say the following events occur between you and your wife/partner?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>	
25.	Have a stimulating exchange of ideas	1	2	3	4	5	6	H25.
26.	Laugh together	1	2	3	4	5	6	H26.
27.	Calmly discuss something	1	2	3	4	5	6	H27.
28.	Work together on a project	1	2	3	4	5	6	H28.

These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. **(Check yes or no).**

29. Being too tired for sex. (1) ☐ Yes (5) ☐ No H29.

30. Not showing love. (1) ☐ Yes (5) ☐ No H30.

31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the number which best describes the degree of happiness, all things considered, of your relationship. H31.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
1	2	3	4	5	6	7

32. Please check one of the following statements to best describe how you feel about the **future** of your relationship. H32.

(1).___I want desperately for my relationship to succeed, and would go to almost any length to see that it does.

(2).___I want very much for my relationship to succeed, and will do all I can to see that it does.

(3).___I want very much for my relationship to succeed, and will do my fair share to see that it does.

(4).___It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.

(5).___It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

(6).___My relationship can never succeed, and there is no more that I can do to keep the relationship going.

33. Considering **only the positive feelings** you have toward your wife/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

H33.

Not At All Positive					Extremely Positive				
1	2	3	4	5	6	7	8	9	10

34. Considering **only the negative feelings** you have toward your wife/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative					Extremely Negative				
1	2	3	4	5	6	7	8	9	10

CURRENT FAMILY SECTION

Please indicate the extent to which each of the following items describes your current family (your household).

		Strongly Disagree			Strongly Agree		
1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
2.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	M3.
4.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
5.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
6.	We can express feelings to each other.	1	2	3	4	5	M6.
7.	There are lots of bad feelings in the family.	1	2	3	4	5	M7.
8.	We feel accepted for who we are.	1	2	3	4	5	M8.
9.	Making decisions is a problem for our family.	1	2	3	4	5	M9.
10.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
11.	We don't get along well together.	1	2	3	4	5	M11.
12.	We confide in each other.	1	2	3	4	5	M12.

YOUR HEALTH AND MOOD SECTION

1. In general, would you say your health is: I1.
(1) ☐ Excellent (2) ☐ Very Good (3) ☐ Good (4) ☐ Fair (5) ☐ Poor
2. Have you **ever in your life** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14.
(1) ☐ Yes (5) ☐ No (Skip to Question 3)
- 2a. If there was such a two-week period, did your work or relationships suffer? I14a.
(1) ☐ Yes (5) ☐ No
- 2b. If there was such a two-week period, did you get counseling or psychotherapy? I14b.
(1) ☐ Yes (5) ☐ No
- 2c. If there was such a two-week period, did you get medication for this condition? I14c.
(1) ☐ Yes (5) ☐ No
3. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
(1) ☐ Yes (5) ☐ No (Skip to Question 4)
- 3a. If there was such a two-week period (**in the past 6 months**), did your work or relationships suffer? I12a.
(1) ☐ Yes (5) ☐ No
- 3b. If there was such a two-week period (**in the past 6 months**), did you get counseling or psychotherapy? I12b.
(1) ☐ Yes (5) ☐ No
- 3c. If there was such a two-week period, (**in the past 6 months**) did you get medication for this problem? I12c.
(1) ☐ Yes (5) ☐ No
4. Are you **currently** receiving counseling, psychotherapy, or medication for depression or emotional problems? I13.
(1) ☐ Yes (5) ☐ No

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		<u>1</u> <u>Not at all</u>	<u>2</u> <u>A little</u>	<u>3</u> <u>Quite a bit</u>	<u>4</u> <u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would ask the dentist exactly what s/he was going to do.	1	5	L1_1
b.	I would take a tranquilizer or have a drink before going.	1	5	L1_2
c.	I would try to think about pleasant memories.	1	5	L1_3
d.	I would want the dentist to tell me when I would feel pain.	1	5	L1_4
e.	I would try to sleep.	1	5	L1_5
f.	I would watch all the dentist's movements and listen for the sound of the drill.	1	5	L1_6
g.	I would watch the flow of water from my mouth to see if it contained blood.	1	5	L1_7
h.	I would do mental puzzles in my mind.	1	5	L1_8

2. Imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do?

		YES	NO	
a.	I would sit by myself and have as many daydreams and fantasies as I could.	1	5	L2_1
b.	I would stay alert and try to keep myself from falling asleep.	1	5	L2_2
c.	I would exchange life stories with the other hostages.	1	5	L2_3
d.	If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.	1	5	L2_4
e.	I would watch every movement of my captors and keep an eye on their weapons.	1	5	L2_5
f.	I would try to sleep as much as possible.	1	5	L2_6
g.	I would think about how nice it's going to be when I get home.	1	5	L2_7
h.	I would make sure I knew where every possible exit was.	1	5	L2_8

3. Imagine that due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off has been made and will be announced in several days. Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.	1	5	L3_1
b.	I would review the list of duties for my present job and try to figure out if I had fulfilled them all.	1	5	L3_2
c.	I would go to the movies to take my mind off things.	1	5	L3_3
d.	I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.	1	5	L3_4
e.	I would push all thoughts of being laid off out of my mind.	1	5	L3_5
f.	I would tell my spouse that I'd rather not discuss my chances of being laid off.	1	5	L3_6
g.	I would try to think which employees in my department the supervisor might have thought had done the worst job.	1	5	L3_7
h.	I would continue doing my work as if nothing special was happening.	1	5	L3_8

4. Imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.	1	5	L4_1
b.	I would make small talk with the passenger beside me.	1	5	L4_2
c.	I would watch the end of the movie, even if I had seen it before.	1	5	L4_3
d.	I would call for the flight attendant and ask her/him exactly what the problem was.	1	5	L4_4
e.	I would order a drink or tranquilizer from the stewardess.	1	5	L4_5
f.	I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.	1	5	L4_6
g.	I would talk to the passenger beside me about what might be wrong.	1	5	L4_7
h.	I would settle down and read a book or magazine or write a letter.	1	5	L4_8

5. This set of questions deals with ways you've been coping with the stress in your life that goes with your wife/partner possibly having the altered BRCA1 gene associated with risk for breast cancer. Obviously, different people deal with this stress in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7_a.
b.	I've been concentrating my efforts on doing something about her situation.	1	2	3	4	L7_b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7_c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7_d.
e.	I've been getting emotional support from others.	1	2	3	4	L7_e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7_f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7_g.
h.	I've been refusing to believe that it is possible she has the gene.	1	2	3	4	L7_h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7_i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7_j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7_k.
l.	I've been trying to come up with a strategy for what to do.	1	2	3	4	L7_l.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7_m.
n.	I've been giving up the attempt to cope.	1	2	3	4	L7_n.
o.	I've been accepting the possibility that she might have the gene.	1	2	3	4	L7_o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7_p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7_q.
r.	I've been learning to live with the possibility she might have the gene.	1	2	3	4	L7_r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7_s.
t.	I've been praying or meditating.	1	2	3	4	L7_t.
u.	I've been making fun of the situation.	1	2	3	4	L7_u.
v.	I've been giving pep talks and encouraging my wife/partner.	1	2	3	4	L7_v.
w.	I've been denying or hiding my anger around my wife/partner.	1	2	3	4	L7_w.
x.	I've been denying or hiding my own worries around my wife/partner.	1	2	3	4	L7_x.
y.	I've been trying to give my wife/partner opportunities to talk about her worries.	1	2	3	4	L7_y.
z.	I've been trying to find out what my wife/partner is feeling.	1	2	3	4	L7_z.
aa.	I've been avoiding talking about my own problems around my wife/partner.	1	2	3	4	L7_aa.
bb.	I've acted more positive around my wife/partner than I feel.	1	2	3	4	L7_bb.

The following questions concern coping with your wife/partner's diagnosis and treatment for cancer:

6. **At your worst**, how distressed did you feel about your wife/partner's diagnosis and treatment of cancer? L8.

Not at All Very Much
1 2 3 4 5 6 7

7. During that time, did you ever have two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually like to do for fun? L9.
- (1) ☐ Yes (5) ☐ No (Skip to Question 8)

- a. If there was such a two-week period, did your work or relationships suffer? L9a.
- (1) ☐ Yes (5) ☐ No

- b. If there was such a two-week period, did you get counseling or psychotherapy? L9b.
- (1) ☐ Yes (5) ☐ No

- c. If there was such a two-week period, did you get medication for this problem? L9c.
- (1) ☐ Yes (5) ☐ No

8. For each of the statements on the following page, indicate the degree to which this change occurred in your life as a result of your wife/partner being diagnosed and treated for breast cancer. Please use the following scale:

- 1 = I experienced **no** change as a result of my wife/partner's being diagnosed and treated for cancer.
- 2 = I experienced this change to a **very small degree** as a result of my wife/partner's being diagnosed and treated for cancer.
- 3 = I experienced this change to a **small degree** as a result of my wife/partner's being diagnosed and treated for cancer.
- 4 = I experienced this change to a **moderate degree** as a result of my wife/partner's being diagnosed and treated for cancer.
- 5 = I experienced this change to a **great degree** as a result of my wife/partner's being diagnosed and treated for cancer.
- 6 = I experienced this change to a **very great degree** as a result of my wife/partner's being diagnosed and treated for cancer.

- ☐ Does not apply because I was not with my wife/partner when she was being treated for breast cancer. L6.

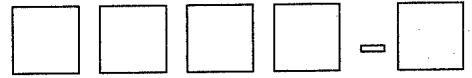
		<i>No Change</i>	<i>Very Small Degree</i>	<i>Small Degree</i>	<i>Moderate Degree</i>	<i>Great Degree</i>	<i>Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6_a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6_b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6_c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6_d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6_e.
f.	Knowing that I can count on people in times of trouble.	1	2	3	4	5	6	L6_f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6_g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6_h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6_i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6_j.
k.	Appreciating each day.	1	2	3	4	5	6	L6_k.
l.	Having compassion for others.	1	2	3	4	5	6	L6_l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6_m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6_n.

9. During the time in which your wife/partner was being treated for breast cancer, how often did you do the following to help her manage the emotional distress?

☐ Does not apply because I was not with my wife/partner when
(-8) she was being treated for breast cancer.

		Never Very Often					
		1	2	3	4	5	
1.	Gave her advice?	1	2	3	4	5	L10a.
2.	Went out of your way not to upset her?	1	2	3	4	5	L10b.
3.	Agreed with her to avoid an argument?	1	2	3	4	5	L10c.
4.	Acted more optimistic than you felt?	1	2	3	4	5	L10d.
5.	Kept your own problems to yourself?	1	2	3	4	5	L10e.
6.	Made up after an argument more quickly than before?	1	2	3	4	5	L10f.
7.	Apologized even when you didn't feel you were wrong?	1	2	3	4	5	L10g.
8.	Told her to calm down or relax?	1	2	3	4	5	L10h.
9.	Hid information that may upset her?	1	2	3	4	5	L10i.
10.	Stayed out of her problems?	1	2	3	4	5	L10j.
11.	Let your own problems take a "back seat" to her needs?	1	2	3	4	5	L10k.
12.	Gave her space when she was upset?	1	2	3	4	5	L10l.

We thank you for all of your valued participation in this study.



WOMEN'S HEALTH STUDY

Spouse Post-Results Questionnaire

Today's Date _____

ID# _____

Spouse Post-Results Questionnaire
(8 Month Follow-Up after Wife/Partner Received Results)

Genetic Testing

1. Did you go with your wife to get her test results? P6

(1) ☐ Yes (5) ☐ No (-8) ☐ Not Applicable (she received results by mail or over the telephone)

2. To your understanding, what were the results of your wife/partner's genetic testing? P5

0 ☐ An altered gene was NOT FOUND for either BRCA1 or BRCA2

└─ Even though no alteration was found for BRCA1 or BRCA2, Do you believe there is a possibility that your wife/partner has another altered gene conveying an increased risk for breast and ovarian cancer?

(1) ☐ Yes (5) ☐ No

N13

1 ☐ An altered gene was FOUND for either BRCA1 or BRCA2

3 ☐ I don't know the results

3. When your wife/partner received her genetic test results, what were your reactions?

☐ Not Applicable -- I don't Know my wife/partner's results.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
		1	2	3	4	5
a.	I felt wonderful.	1	2	3	4	5
b.	I felt depressed.	1	2	3	4	5
c.	I felt she had been told what she knew all along.	1	2	3	4	5
d.	I felt relieved about being more certain.	1	2	3	4	5
e.	I did not believe the results.	1	2	3	4	5
f.	I fell apart emotionally.	1	2	3	4	5
g.	I felt anxious.	1	2	3	4	5
h.	I felt angry.	1	2	3	4	5

B18c_a.

B18c_b.

B18c_c.

B18c_d.

B18c_e.

B18c_f.

B18c_g.

B18c_h.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
i.	I felt prepared for the future.	1	2	3	4	5
j.	I felt worried about the future.	1	2	3	4	5
k.	I felt she had done all she needed to do.	1	2	3	4	5
l.	I did not feel very differently.	1	2	3	4	5
m.	[For those who have daughters]. I wanted my daughters to be tested as soon as possible.	1	2	3	4	5

B18c_i.

B18c_j.

B18c_k.

B18c_l.

B18c_m.

4. To what extent did you do the following after your wife/partner got her genetic results?

		<i>Never</i>			<i>Very Often</i>	
a.	Gave her advice?	1	2	3	4	5
b.	Went out of your way not to upset her?	1	2	3	4	5
c.	Agreed with her to avoid an argument?	1	2	3	4	5
d.	Acted more optimistic than you felt?	1	2	3	4	5
e.	Kept your own problems to yourself?	1	2	3	4	5
f.	Made up after an argument more quickly than before?	1	2	3	4	5
g.	Apologized even when you didn't feel you were wrong?	1	2	3	4	5
h.	Told her to calm down or relax?	1	2	3	4	5
i.	Hid information that may upset her?	1	2	3	4	5
j.	Stayed out of her problems?	1	2	3	4	5
k.	Let your own problems take a "back seat" to her needs?	1	2	3	4	5
l.	Gave her space when she was upset?	1	2	3	4	5

L10a

L10b

L10c

L10d

L10e

L10f

L10g

L10h

L10i

L10j

L10k

L10l

5. How distressed were you when you heard your wife's genetic test results?

P2a

Not At All Distressed				Very Distressed	Doesn't Apply <i>I don't know what her results are</i>
1	2	3	4	5	-8

6. In your opinion, how distressed was your wife/partner when she received genetic test results?

P3a

Not At All Distressed				Very Distressed
1	2	3	4	5

7. Overall, do you regret your wife/partner's decision to obtain her results?

B71b

Not At All				Very Much So
1	2	3	4	5

8. Do you think it is beneficial to have genetic testing for risk of breast and ovarian cancer available to women?

B55

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

For the next set of questions, we would like to ask about the impact your wife/partner's receiving results has had on different areas of your family's life.

9. On the whole, what effect has her testing had on your life?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N15

10. Think about your everyday family life. What effect would you say getting the genetic test results has had?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N16

11. What effect has your wife/partner getting her results had on your work in and outside of the home?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N17

12. How has it affected your anxiety about the future?

Less Anxiety	No Change	More Anxiety
1	2	3

N18

13. What effect has your wife/partner getting her results had on your concerns for your child's/children's future?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	Not Applicable
1	2	3	4	5	-8

N19

14. Psychologists have developed a standardized scale for comparing stressful situations with 0 representing no stress and 100 representing the greatest stress. Using this scale, North American samples have given the following ratings to some stressful events:

Change in residence is assigned a stress score of 20

Pregnancy is 40

Death of a close family member is 63

Death of a spouse is 100

Keeping in mind the ratings listed above, Please use any number between 0-100 with 0 representing no stress and 100 representing the greatest stress:

- a. For only those whose wives/partners have had breast or ovarian cancer, how would you rate your stress level when you heard your had wife been diagnosed?

Wife's diagnosis of Cancer _____

N3b

- b. Now, how would you rate your stress when you heard the results of your wife's genetic testing?

Stress of hearing wife's genetic results _____

N4

15. How often have you discussed genetic testing for breast and ovarian cancer with your wife/partner?

B51

Never	Rarely	Sometimes	Often
1	2	3	4

15a. When you have these discussions, who generally initiates them?

B52

You	Your Wife/partner	Equally	Not Applicable
1	2	3	-8

15b. How satisfied are you with these discussions?

B53

Not At All	A Little	Somewhat	A Great Deal	Not Applicable
1	2	3	4	-8

16. How often does your wife/partner express concern and seek support from you about the risk of breast and ovarian cancer to herself and women in her family?

B49

Never	Rarely	Sometimes	Often
1	2	3	4

16a. How much of a burden is this on you?

B50

Not At All	A Little	Somewhat	A Great Deal	Not Applicable
1	2	3	4	-8

17. Overall, how much do you want your opinion to be taken into account in your wife/partner's decisions **about what to do about her risk** for breast and ovarian cancer?

B58

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

18. Overall, what do you believe your wife/partner's risk to be of developing breast or ovarian cancer (or developing breast or ovarian cancer again) **in the near future**?

B9b

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

19. Overall, what do you believe her risk to be of developing breast or ovarian cancer (or developing breast or ovarian cancer again) **at some point in her lifetime?**

B10b

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

20. At the present time, do you feel you are adequately informed concerning your wife/partner's risk for cancer and what can be done about it?

B43a

Not At All						Very Much
1	2	3	4	5	6	7

21. At the present time, do you feel you are adequately informed about the benefits and drawbacks of options available to women who have an altered BRCA1/BRCA2 gene?

B46

Not At All						Very Much
1	2	3	4	5	6	7

22. How often do you worry about your wife/partner developing breast/ovarian cancer (again)?

Not At All				All the Time
1	2	3	4	5

B27aa

23. To what extent do these worries interfere with your every day life?

Not At All				All the Time
1	2	3	4	5

B28a

24. How often do you worry about developing cancer yourself?

Not At All				All the Time
1	2	3	4	5

B31

Symptoms of Strain

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Circle The Answer Which Best Reflects How Much That Symptom Has Bothered You During the Past Three Months.*

		<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>	
1.	Suddenly scared for no reason	1	2	3	4	K1
2.	Feeling fearful	1	2	3	4	K2
3.	Faintness, dizziness, or weakness	1	2	3	4	K3
4.	Nervousness or shakiness inside	1	2	3	4	K4
5.	Heart pounding or racing	1	2	3	4	K5
6.	Trembling	1	2	3	4	K6
7.	Feeling tense or keyed up	1	2	3	4	K7
8.	Headaches	1	2	3	4	K8
9.	Spells of terror or panic	1	2	3	4	K9
10.	Feeling restless, can't sit still	1	2	3	4	K10
11.	Feeling low in energy--slowed down	1	2	3	4	K11
12.	Blaming yourself for things	1	2	3	4	K12
13.	Crying easily	1	2	3	4	K13
14.	Loss of sexual interest or pleasure	1	2	3	4	K14
15.	Poor appetite	1	2	3	4	K15
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16
17.	Feeling hopeless about the future	1	2	3	4	K17
19.	Feeling blue	1	2	3	4	K19
19.	Feeling lonely	1	2	3	4	K19
20.	Feeling trapped or caught	1	2	3	4	K20
21.	Worrying too much about things	1	2	3	4	K21
22.	Feeling no interest in things	1	2	3	4	K22
23.	Thoughts of ending your life	1	2	3	4	K23
24.	Feeling everything is an effort	1	2	3	4	K24
25.	Feelings of worthlessness	1	2	3	4	K25

26. To what extent are any of the above current symptoms a result of your wife/partner getting genetic testing?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

K26

Your Views of Prevention and Treatment

1. To what extent do you agree or disagree with the following statements?

		Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Somewhat Agree	
a.	In the next year, there will be dramatic breakthroughs in the <u>prevention</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7a
b.	In the next year, there will be dramatic breakthroughs in the <u>treatment</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7b
c.	In the next year, the length of <u>survival</u> after diagnosis of breast cancer will increase.	1	2	3	4	5	N7c
d.	In the next year, the length of <u>survival</u> after diagnosis of ovarian cancer will increase.	1	2	3	4	5	N7d
e.	In the next 5 years, there will be dramatic breakthroughs in the <u>prevention</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7e
f.	In the next 5 years, there will be dramatic breakthroughs in the <u>treatment</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7f
g.	In the next five years, the length of <u>survival</u> after diagnosis of breast cancer will increase.	1	2	3	4	5	N7g
h.	In the next five years, the length of <u>survival</u> after diagnosis of ovarian cancer will increase.	1	2	3	4	5	N7h
i.	In the future, all women will routinely receive genetic testing for risk of breast and ovarian cancer.	1	2	3	4	5	N7i

We thank you for all of your valued participation in this study.

☐ ☐ ☐ ☐ - ☐ ☐ ☐



WOMEN'S HEALTH STUDY

Sister Questionnaire

Today's Date _____

ID _____

SISTER QUESTIONNAIRE

HEALTH SECTION

1. Have you ever been diagnosed with Breast cancer? (1) ☐ Yes (5) ☐ No **B1u.**
2. Have you ever been diagnosed with Ovarian cancer? (1) ☐ Yes (5) ☐ No **B5.**

Please answer the following questions only if you have been diagnosed at any time with breast or ovarian cancer.

I have never been diagnosed with breast or ovarian cancer. ☐ Skip to 11

3. When were you first diagnosed with breast cancer? **B1.**
Month _____ Year _____ ☐ Not Applicable
4. When were you first diagnosed with ovarian cancer? **B5a.**
Month _____ Year _____ ☐ Not Applicable
5. Have you received any of the following treatments? **B4a.**
Chemotherapy (1) ☐ Yes (5) ☐ No **B4b.**
Radiation (1) ☐ Yes (5) ☐ No **B4c.**
Surgery (1) ☐ Yes (5) ☐ No
6. Have you ever had any of the following surgical procedures?
- 6a. **Lumpectomy** (Removal of lump from breast) **B6a.**
(1) ☐ Yes (5) ☐ No If yes, when? Month _____ Year _____ **B6a2.**
- 6b. **Unilateral mastectomy** (Removal of one breast) **B6c.**
(1) ☐ Yes (5) ☐ No If yes, when? Month _____ Year _____ **B6c2.**
- 6c. **Bilateral mastectomy** (Removal of both breasts) **B6e.**
(1) ☐ Yes (5) ☐ No If yes, when? Month _____ Year _____ **B6e2.**
- 6d. **Hysterectomy** (Removal of uterus) **B6d.**
(1) ☐ Yes (5) ☐ No If yes, when? Month _____ Year _____ **B6d2.**
- 6e. **Oophorectomy** (Removal of ovaries) **B6b.**
(1) ☐ Yes (5) ☐ No If yes, when? Month _____ Year _____ **B6b2.**

7. Do you currently consider yourself in remission?
 (1) ☐ Yes (5) ☐ No (3) ☐ I Don't Know

B3.

8. Have you ever had a recurrence of breast or ovarian cancer?
 (1) ☐ Yes (5) ☐ No (3) ☐ I Don't Know

B100.

9. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to the average woman? (Please circle one)

B7.

Much Less Likely			Much More Likely	
1	2	3	4	5

10. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to the women in your family? (Please circle one)

B8.

Much Less Likely			Much More Likely	
1	2	3	4	5

*Skip to
Question 13*

11. How likely did you think you are to develop breast cancer, compared to the average woman? (Please circle one)

B7a.

Much Less Likely			Much More Likely	
1	2	3	4	5

12. How likely did you think you are to develop breast cancer, compared to the women in your family? (Please circle one)

B8a.

Much Less Likely			Much More Likely	
1	2	3	4	5

13. When was the last time you had a mammogram?

B32.

_____ Month _____ Year ☐ This question does not apply because of surgery.
 (-8)

14. How many times have you conducted a breast self-examination (BSE) in the past six months?

B33.

_____ times ☐ This question does not apply because of surgery.
 (-8)

15. In general, would you say your health is:

- ☐ Excellent (1)
 ☐ Very Good (2)
 ☐ Good (3)
 ☐ Fair (4)
 ☐ Poor (5)

I1.

16. Compared to one year ago, how would you rate your health in general now?
(Please Check one only)

- (1) ☐ Much better now than one year ago
 (2) ☐ Somewhat better now than one year ago
 (3) ☐ About the same as one year ago
 (4) ☐ Somewhat worse now than one year ago
 (5) ☐ Much worse than one year ago

I2.

FAMILY HISTORY SECTION

In the next set of questions, we are interested in learning about your family's experience with breast cancer.

1. Have any of your relatives been diagnosed with breast cancer?

B91.

- (1) ☐ Yes
 (5) ☐ No
 (3) ☐ I Don't Know

2. If Yes, how many of the following relatives been affected by (diagnosed with) breast cancer? (*How many relatives for each category where applicable?*)

	<u>Relative:</u>	<u>How Many?</u>
a.	Sister(s)	
b.	Mother	
c.	Grandmother(s) Maternal	
d.	Grandmother(s) Paternal	
e.	Aunt(s) Maternal	
f.	Aunt(s) Paternal	
g.	Cousin(s) Maternal	
h.	Cousin(s) Paternal	
i.	Wife	
j.	Daughter(s)	

B92a.

B92b.

B92c1.

B92c2.

B92d1.

B92d2.

B92e1.

B92e2.

B92f.

B92g.

3. Do you think that your family is at an increased risk for breast cancer compared with other families?

B99.

(1) ☐ Yes (5) ☐ No (3) ☐ I Don't Know

IF ANSWERED NO, GO TO QUESTION 7

4. How distressing is it for you to know that women in your family may be at increased risk for breast cancer because of their family history?

B66a.

Not At All Distressing		Very Distressing		
1	2	3	4	5

5. Do you discuss your family's **increased risk for breast cancer** with any of the following women in your family? (Circle *Not Applicable* if you do not have any living relatives in that category.)

		Yes	No	Not Applicable	
a.	Mother	1	5	9	B93a.
b.	Grandmother(s)	1	5	9	B93b.
c.	Aunt(s)	1	5	9	B93c.
d.	Cousin(s)	1	5	9	B93d.
e.	Wife	1	5	9	B93e.
f.	Daughter(s)	1	5	9	B93f.
f.	Other women family members	1	5	9	B93g.

6. Compared to how often you now talk to the women in your family about their **risk for breast cancer**, how much would you prefer to talk to them about this topic?

B94.

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

7. Do you wish you had more information about your family's risk for breast cancer?

B97.

(1) ☐ Yes (5) ☐ No (3) ☐ No Opinion

8. How often do you discuss your family's risk for breast cancer with **your sister** who gave us your name?

B75.

Never	Rarely	Sometimes	Often
1	2	3	4

- 8a. If you have these discussions, who generally initiates them?

B75a.

You	Your Sister	Equally	No discussions
1	2	3	4

- 8b. How satisfied are you with these discussions?

B75b.

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

9. How often does **your sister** seek your support concerning the risk of breast cancer to women in your family?

B49a.

Never	Rarely	Sometimes	Often
1	2	3	4

10. How much of a **burden** is this on you?

B50.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

GENETIC TESTING SECTION

Now, we have some questions about breast cancer diagnosis, treatment, and genetic testing.

1. We would like to know how much you have been informed about breast cancer. To what extent do you agree with the following statements?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>
		1	2	3	4	5	9
a.	Mammography is effective in the early detection of breast cancer in women.						

B20a.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>	
		1	2	3	4	5	9	
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	B20c.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.

There is a test now available that will allow individuals to learn whether they have an altered gene (BRCA-1 or BRCA-2) which conveys an increased risk for developing breast cancer.

2. Were you aware that **women** are being offered the opportunity to take this test? B77a.
 (1) ☐ Yes (5) ☐ No

3. Do you discuss **genetic testing for breast cancer** susceptibility with any of the following women in your family? (Circle *Not Applicable* if you do not have any living relatives in that category.)

		<i>Yes</i>	<i>No</i>	<i>Not Applicable</i>	
a.	Sister(s)	1	5	9	B95a.
b.	Mother	1	5	9	B95b.
c.	Grandmother(s)	1	5	9	B95c.
d.	Aunt(s)	1	5	9	B95d.
e.	Cousin(s)	1	5	9	B95e.
f.	Wife	1	5	9	B95f.
f.	Daughter(s)	1	5	9	B95g.
g.	Other women family members	1	5	9	B95h.

4. Compared to how often you now talk to the women in your family about **genetic testing for breast cancer**, how much would you prefer to talk to them about this topic?

B96.

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

5. Do you wish you had more information about genetic testing?

B98.

(1) ☐ Yes (5) ☐ No (3) ☐ No Opinion

6. How often do you discuss genetic testing for breast cancer with **your** sister (who gave us your name)?

B51a.

Never	Rarely	Sometimes	Often
1	2	3	4

- 6a. If you have these discussions, who generally initiates them?

B52a.

You	Your Sister	Equally	No discussions
1	2	3	4

- 6b. How satisfied are you with these discussions?

B53.

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

7. What are **your** plans concerning this genetic test at the present time?
(Please check **one** response).

B15c.

- (1)_____ I will definitely take the test soon.
 (2)_____ I will definitely take the test, but I am not sure when.
 (3)_____ I will probably take the test.
 (4)_____ I am undecided whether I will take the test.
 (5)_____ I will probably not take the test.
 (6)_____ I will definitely not take the test.

8. If you think you will probably or definitely take the test, what are your reasons for doing so? **B16a.**
(Please check all that apply).

- (1)_____ To make decisions about family planning.
- (2)_____ To find out the risk that may be transmitted to my children.
- (3)_____ To find out about the risk to a daughter who is too young to be tested.
- (4)_____ Family members want me to get testing.
- (5)_____ I just want to know whether I have an altered gene.
- (6)_____ I am worried about my own risk for cancer.
- (7)_____ Other (describe) _____

9. If you **do not** think you will probably or definitely take the test, what are your reasons for **not** doing so? **(Please check all that apply).** **B17a.**

- (1)_____ I am happier not knowing.
- (2)_____ I do not see any reason for learning if I have an altered gene.
- (3)_____ It would be too upsetting to learn that I have an altered gene.
- (4)_____ I am too worried about women in my family.
- (5)_____ I believe I already know whether I have an altered gene.
- (6)_____ There would not be much I could do if I found out I had an altered gene.
- (7)_____ I do not feel able emotionally to deal with testing.
- (8)_____ Family members do not want me to get testing.
- (9)_____ Risk to my insurance coverage.
- (10)_____ Too much hassle
- (11)_____ Other (describe) _____

10. How distressing is it for you to know that you may carry an altered gene which conveys an increased risk of breast cancer? **B76.**

Not At All Distressed				Very Distressed	
1	2	3	4	5	

11. Overall, how important are the opinions of the following family members in your decision whether to be tested for an altered gene associated with increased risk for breast cancer? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some-what	A Great Deal	Not Applicable
a.	Sister(s)'s opinion matters	1	2	3	4	9
b.	Spouse/Partner's opinion matters	1	2	3	4	9
c.	Mother's opinion matters	1	2	3	4	9
d.	Daughter's opinion matters	1	2	3	4	9
e.	Other family member(s)'s opinions matter	1	2	3	4	9

B78a.

B78b.

B78c.

B78d.

B78e.

12. How pressured do you feel from the following family members to get tested for an altered gene? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some-what	A Great Deal	Not Applicable
a.	Sister(s)	1	2	3	4	9
b.	Spouse/Partner	1	2	3	4	9
c.	Mother	1	2	3	4	9
d.	Daughter	1	2	3	4	9
e.	Other family member(s)	1	2	3	4	9

B79a.

B79b.

B79c.

B79d.

B79e.

13. How much of a **burden** is it **on you** when the women in your family pressure you to get tested for an altered gene?

No Burden	A Little Burden	Some Burden	A Great Burden	Not applicable, No Pressure
1	2	3	4	5

B80.

14. How distressed would you be if you took the test and found that you **did not** have an altered gene which conveys increased risk of breast cancer?

B70a.

Not At All Distressed				Very Distressed
1	2	3	4	5

15. If you were to take the test and find out that you **did not have** an altered gene which conveys increased risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	I would feel wonderful.	1	2	3	4	5	B81a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B81b.
c.	I would feel relieved.	1	2	3	4	5	B81c.
d.	I would not believe the results.	1	2	3	4	5	B81d.
e.	I would fall apart emotionally.	1	2	3	4	5	B81e.
f.	I would feel guilty.	1	2	3	4	5	B81f.
g.	I would still feel anxious.	1	2	3	4	5	B81g.
h.	I would feel angry.	1	2	3	4	5	B81h.
i.	I would feel prepared for the future.	1	2	3	4	5	B81i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B81j.
k.	I would not feel very differently.	1	2	3	4	5	B81k.

16. How distressed would you be if you took the test and found that you **did have** an altered gene which conveys increased risk for breast cancer?

B69a.

Not At All Distressed		Very Distressed		
1	2	3	4	5

17. If you were to take the test and find out that you **had** an altered gene, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	I would feel relieved about being more certain.	1	2	3	4	5	B82a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B82b.
c.	I would not believe the results.	1	2	3	4	5	B82c.
d.	I would feel guilty.	1	2	3	4	5	B82d.
e.	I would be depressed.	1	2	3	4	5	B82e.
f.	I would feel worried about the future.	1	2	3	4	5	B82f.
g.	I would just fall apart emotionally.	1	2	3	4	5	B82g.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
		1	2	3	4	5
h.	I would feel anxious.	1	2	3	4	5
i.	I would feel angry.	1	2	3	4	5
j.	I would not feel very differently.	1	2	3	4	5

B82h.

B82i.

B82j.

		<i>Not At All</i>			<i>All The Time</i>	
		1	2	3	4	5
18.	How often do you worry about having an altered gene associated with risk for breast cancer among women?	1	2	3	4	5
19.	To what extent do any worries you have about this genetic alteration interfere with every day life?	1	2	3	4	5
20.	How often do you worry about women in your family developing breast cancer?	1	2	3	4	5
21.	How often do you worry about developing cancer yourself?	1	2	3	4	5
22.	How much do worries about developing cancer interfere with your everyday life?	1	2	3	4	5

B83.

B84.

B85.

B86.

B87.

23. How likely do you think it is that you have an altered gene which conveys increased risk for breast cancer in women relatives? (Please circle one)

B88.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

24. How much would it affect your health in the future if you had an altered gene which conveys increased risk for breast cancer in women relatives?

B89.

☐ Not at All ☐ A Little ☐ Somewhat ☐ A Great Deal ☐ I Don't Know
 (1) (2) (3) (4) (5)

25. Overall, what do you think your risk is of developing cancer (or developing cancer again) in the future?

B90.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

SYMPTOMS OF STRAIN SECTION

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the Past Three Months.*

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

FAMILY RELATIONSHIPS SECTION

1. Please indicate the extent to which each of the following items currently describes **the family in which you grew up.**

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
b.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
c.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	M3.
d.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
e.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
f.	We can express feelings to each other.	1	2	3	4	5	M6.
g.	There are lots of bad feelings in the family.	1	2	3	4	5	M7.
h.	We feel accepted for who we are.	1	2	3	4	5	M8.
i.	Making decisions is a problem for our family.	1	2	3	4	5	M9.
j.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
k.	We don't get along well together.	1	2	3	4	5	M11.
l.	We confide in each other.	1	2	3	4	5	M12.

2. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.

☐ Yes ☐ No

- 2a. Do you have that kind of relationship with **your sister** (who gave us your name)? C21c.
- ☐ Yes ☐ No

3. How often do you talk to **your sister**? (check one) C22.

☐ Most every day
☐ A few times a week
☐ A few times a month
☐ Once a month
☐ Less than once a month
☐ Less than once a year
☐ Never

BACKGROUND DATA SECTION

Now, we'd like to know more about you.

1. Date of Birth _____ Month _____ Day _____ Year A1.

2. Ethnic Background: White ☐ 1 Black ☐ 4 A2.
 Hispanic ☐ 2 Asian ☐ 5
 Native American ☐ 3 Other ☐ 6

3. Religion: Catholic ☐ 1 Protestant ☐ 4 A3.
 Jewish ☐ 2 Buddhist ☐ 5
 Muslim ☐ 3 Other ☐ 6
 None ☐ 7

- 3a. How often do you attend religious services? A3a.
 ☐ 1 Less Than Once a Month ☐ 5 A Few Times A Month or More

- 3b. How important are religious and spiritual beliefs in your life? A3b.
 Not at All 1 2 3 4 5 Very Important

4. Are you currently (please check one)? A4.
 1 ☐ Single
 2 ☐ Married
 3 ☐ Not married, but living in a steady,
 marriage-like relationship
 4 ☐ Separated
 5 ☐ Divorced
 6 ☐ Widowed

5. If you **are** currently married, what was the date of your current marriage? A5.
 Month _____ Year _____

- 5a. Is this your first marriage? (1) ☐ Yes (5) ☐ No A5a.

6. How many children do you have? _____ A6.
 6a. Number of children living at home? _____ A6a.
 6b. Number who are under age 6? _____ A6b.
 6c. Number of Daughters? _____ A6c.

7. Do you plan to have more children? (1) ☐ Yes (5) ☐ No (3) ☐ Undecided A12.
 7a. If yes, how many more children? _____ A12a.

8. Are you currently working for pay outside the home? A 7.
(1) ☐ Yes (5) ☐ No

9. If yes, about how many hours per week are you working for pay? A 8.
Less than 10 10-20 21-30 31-40 41 or more
☐ ☐ ☐ ☐ ☐
(1) (2) (3) (4) (5)

10. What is the highest level of education you have completed? (Check one) A 9.
1 ☐ Less than 9th grade 5 ☐ Completed college
2 ☐ Dropped out of high school 6 ☐ Some graduate or professional training
3 ☐ Completed high school 7 ☐ Completed graduate or professional training
4 ☐ Some college

The following two questions are optional, but we hope that you will provide this information.

11. What is your household's total income? (Check one) A 10.
(1) ☐ Less than \$10,000 (4) ☐ \$30,000 to \$39,999 (7) ☐ \$60,000 to \$69,999
(2) ☐ \$10,000 to \$19,999 (5) ☐ \$40,000 to \$49,999 (8) ☐ Greater than \$69,999
(3) ☐ \$20,000 to \$29,999 (6) ☐ \$50,000 to \$59,999

12. How many people (adults and children) does this income support? _____ A 11.

THANK YOU VERY MUCH
FOR YOUR PARTICIPATION.

-

LONG TERM FOLLOW-UP STUDY

Questionnaire

TODAY'S DATE _____

ID _____

LONGITUDINAL ASSESSMENT--for Women

This is a follow up questionnaire from a joint project being conducted by the University of Michigan Medical Center and the University of Pennsylvania Cancer Center. It is for people who have received results of genetic testing for an altered gene associated with risk of breast cancer and ovarian cancer. As genetic testing becomes more routine, it is important for us to know how this information affects people's quality of life and future health care decisions. Thank you very much for your participation!

Health History Section

1. Have you ever been diagnosed with breast cancer? B1u.
 (1) ☐ Yes (5) ☐ No If yes, when? (Month/Year) _____ B1.
 - 1a. Have you ever had a second diagnosis of breast cancer? B1c.
 (1) ☐ Yes (5) ☐ No If yes, when? (Month/Year) _____ B1d.
 What Type? (1) ☐ Recurrence or (2) ☐ Second Primary B1e.
 - 1b. Do you currently consider yourself in remission? B3a.
 (1) ☐ Yes (5) ☐ No If yes, how long in months? _____ (Months) B3b.
2. Have you ever been diagnosed with ovarian cancer? B5.
 (1) ☐ Yes (5) ☐ No If yes, when? (Month/Year) _____ B5a.
 - 2a. Do you currently consider yourself in remission? B3c.
 (1) ☐ Yes (5) ☐ No If yes, how long in months? _____ (Months) B3d.
3. Have you ever had any of the following surgical procedures?
 - 3a. **Lumpectomy** (Removal of lump from breast) B6a.
 (1) ☐ Yes (5) ☐ No If yes, when? (Month/Year) _____ B6a2.
 Reason(s): _____ B6a3.
 - 3b. **Unilateral mastectomy** (Removal of one breast) B6c.
 (1) ☐ Yes (5) ☐ No If yes, when? (Month/Year) _____ B6c2.
 Reason(s): _____ B6c3.
 - 3c. **Second Unilateral mastectomy** B6f.
 (1) ☐ Yes (5) ☐ No If yes, when? (Month/Year) _____ B6f2.
 Reason(s): _____ B6f3.
 - 3d. **Bilateral mastectomy** (Removal of both breasts) B6e.
 (1) ☐ Yes (5) ☐ No If yes, when? (Month/Year) _____ B6e2.
 Reason(s): _____ B6e3.

3. Have you ever had any of the following surgical procedures (continued)?

3e. **Oophorectomy** (Removal of ovaries)

B6b.

(1) ☐ Yes (5) ☐ No If yes, when? (Month/Year) _____

B6b2.

Reason(s): _____

B6b3.

3f. **Hysterectomy** (Removal of uterus)

B6d.

(1) ☐ Yes (5) ☐ No If yes, when? (Month/Year) _____

B6d2.

, Reason(s): _____

B6d3.

5. When was the last time you had a mammogram?

B32.

(Month/Year) _____ ☐ This question does not apply because of surgery.
(-8)

6. How many times have you conducted a breast self-examination in the past six months?

B33.

_____ times ☐ This question does not apply because of surgery.
(-8)

7. How confident are you that you will perform breast self examination as **frequently** as needed?

Not At All So						Very Much		Does Not Apply because of surgery
1	2	3	4	5	6	7	-8	

B34a.

8. How confident are you that you will perform breast self examination as **carefully and competently** as needed?

Not At All So						Very Much		Does Not Apply because of surgery
1	2	3	4	5	6	7	-8	

B34b.

9. How confident are you that you would be able to detect a change in your breasts using breast self examination?

Not At All So						Very Much		Does Not Apply because of surgery
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B34c.

1	2	3	4	5	6	7	-8
---	---	---	---	---	---	---	----

Personal Attitudes Section

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>					<i>Strongly Agree</i>	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5		L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5		L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5		L5c.
d.	There is nothing more important than good health.	1	2	3	4	5		L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5		E1.
f.	It's easy for me to relax.	1	2	3	4	5		E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5		E3.
h.	I always look on the bright side of things.	1	2	3	4	5		E4.
i.	I'm always optimistic about my future.	1	2	3	4	5		E5.
j.	I enjoy my friends a lot.	1	2	3	4	5		E6.
k.	It's important for me to keep busy.	1	2	3	4	5		E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5		E8.
m.	Things never work out the way I want them to.	1	2	3	4	5		E9.
n.	I don't get upset too easily.	1	2	3	4	5		E10.

o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

2. Now, we would like to ask you some questions about your concerns of breast cancer.

		<i>Not At All</i>				<i>All The Time</i>	
a.	How often do you worry about developing breast cancer or developing breast cancer again?	1	2	3	4	5	B27.
b.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
c.	How often do you worry about developing ovarian cancer or developing ovarian cancer again?	1	2	3	4	5	B110.
d.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B111.
e.	How often do you worry about having an altered gene associated with risk for breast or ovarian cancer?	1	2	3	4	5	B29.
f.	To what extent do worries about having an altered gene interfere with your everyday life?	1	2	3	4	5	B30.
g.	How often do you worry about your relatives developing breast or ovarian cancer?	1	2	3	4	5	B106.
h.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B107.
i.	How often do you worry about your relatives having an altered gene associated with risk for breast and ovarian cancer?	1	2	3	4	5	B108.
j.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B109.

Genetic Testing Section

1. When did you receive your results of genetic testing?

B101.

(Month/Year) _____

2. Did you do any of the following before obtaining your results?

		<u>Yes</u>	<u>No</u>	
a.	Prophylactic Mastectomy	1	5	B102a.
b.	Prophylactic Oophorectomy	1	5	B102b.
c.	Regular Breast Self-Exams (Monthly)	1	5	B102c.
d.	Regular Physical Exams	1	5	B102d.
e.	Regular Mammograms	1	5	B102e.
f.	Encourage your relatives to be tested	1	5	B102f.
g.	Discourage your relatives from being tested	1	5	B102g.

3. Please rate the extent to which each of the following were your reasons for getting your results.

		<div>Not at all</div> <div>Very Much So</div>					
a.	To plan for the future.	1	2	3	4	5	B16b1.
b.	To reduce the uncertainty.	1	2	3	4	5	B16b2.
c.	To know I have to be more careful about doing breast self examinations and getting regular checkups.	1	2	3	4	5	B16b3.
d.	To make decisions about whether to get prophylactic surgery.	1	2	3	4	5	B16b4.
e.	To make decisions about family planning.	1	2	3	4	5	B16b5.

f.	To find out the risk that may be transmitted to my children.	1	2	3	4	5	B16b6.
g.	Family members wanted me to get testing.	1	2	3	4	5	B16b7.
h.	Other (describe)_____	1	2	3	4	5	B16b8.

4. Before getting your test results, how distressing had it been for you to know that your family may be at increased risk for breast or ovarian cancer because of your family history?

Not At All Distressing		Very Distressing		
1	2	3	4	5

B66b.

5. How distressed **did you expect to be** when you were told you have an altered BRCA1/BRCA2 gene (before you received results)?

Not At All Distressed		Very Distressed		
1	2	3	4	5

B68b.

6. How distressed were you when you were told that you had an altered BRCA1 (or BRCA2) gene?

Not At All Distressed		Very Distressed		
1	2	3	4	5

B69b.

7. Overall, do you regret the decision to obtain your results?

Not At All		Very Much So		
1	2	3	4	5

B71a.

8. When you received your results, what were your immediate reactions?

		Not At All		Very Much So		
a.	I felt relieved about being more certain.	1	2	3	4	5

B82a.

b.	I felt I had been told what I knew all along.	1	2	3	4	5	B82b.
c.	I did not believe the results.	1	2	3	4	5	B82c.
d.	I felt guilty.	1	2	3	4	5	B82d.
e.	I was depressed.	1	2	3	4	5	B82e.
f.	I worried about the future.	1	2	3	4	5	B82f.
		Not At All Very Much So					
g.	I thought I would just fall apart emotionally.	1	2	3	4	5	B82g.
h.	I felt anxious.	1	2	3	4	5	B82h.
i.	I felt angry.	1	2	3	4	5	B82i.

9. We are interested in the decisions women make after being notified of the results of their testing. After obtaining your results, which options are you now considering? Please circle one response.

		Definitely Will <u>NOT</u> Do	Probably Will <u>NOT</u> Do	Probably Will Do	Definitely Will Do	Done After Obtaining Results	Does <u>Not</u> Apply to Me	
a.	Prophylactic Oophorectomy	1	2	3	4	5	-8	B103a.
b.	Prophylactic Mastectomy	1	2	3	4	5	-8	B103b.
c.	Regular Breast Self-Exams (Monthly)	1	2	3	4	5	-8	B103c.
d.	Regular Physical Exams	1	2	3	4	5	-8	B103d.
e.	Regular Mammograms	1	2	3	4	5	-8	B103e.
f.	Encouraging my relatives to be tested	1	2	3	4	5	-8	B103f.
g.	Discouraging my relatives from being tested	1	2	3	4	5	-8	B103g.

h.	Telling some of my relatives what my results were	1	2	3	4	5	-8	B103h.
i.	Not telling some of my relatives what my results were	1	2	3	4	5	-8	B103i.

10. For each of the following areas of your life, please indicate how much these decisions/plans have been affected by the results of genetic testing?

		<i>Not at all Affected</i>			<i>Very Much Affected</i>		<i>Not Applicable</i>	
		1	2	3	4	5	-8	
a.	Decisions about having children	1	2	3	4	5	-8	B35c.
b.	Decisions about forms of birth control	1	2	3	4	5	-8	B36c.
c.	Decisions about which steps to take to prevent breast cancer	1	2	3	4	5	-8	B37c.
d.	Decisions about work and career	1	2	3	4	5	-8	B38c.
e.	Decisions about savings and financial planning	1	2	3	4	5	-8	B39c.
f.	Plans for your future	1	2	3	4	5	-8	B40c.
g.	Plans for your daughter's future	1	2	3	4	5	-8	B42c.

11. Do you feel you have enough information about breast cancer to make any decisions that might be necessary?

Not At All						Very Much
1	2	3	4	5	6	7

B43.

12. Do you feel you have enough information about ovarian cancer to make any decisions that might be necessary?

Not At All	Very Much
-------------------	------------------

B43a.

1	2	3	4	5	6	7
---	---	---	---	---	---	---

13. Do you feel you were adequately informed about the benefits and drawbacks of genetic testing for risk of breast and ovarian cancer **before getting your results?**

Not At All						Very Much
1	2	3	4	5	6	7

B44a.

14. Do you **now** feel you are adequately informed about what you can do to reduce your risk of breast cancer since you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B45a.

15. Do you **now** feel you are adequately informed about what you can do to reduce your risk of ovarian cancer since you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B45b.

16. Do you **now** feel you are adequately informed about the benefits and drawbacks of each option available to women who have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B46a.

17. Do you feel you are adequately informed about what it will mean for your children that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much	Not Applicable
1	2	3	4	5	6	7	-8

B47a.

18. How confident are you that **you** will cope effectively with the finding that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
------------	--	--	--	--	--	-----------

B48e.

1	2	3	4	5	6	7
---	---	---	---	---	---	---

19. How confident are you that **your family members** will cope effectively with the finding that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48f.

Coping Section

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of knowing that you have an altered gene associated with increased risk of breast and ovarian cancer. For each of the statements below, indicate the degree to which your life has been affected positively by finding you have an altered gene.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.

k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that goes with knowing you have an altered gene associated with increased risk for breast cancer. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this some</i>	<i>I've been doing this a lot</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.

j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.
		<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this some</i>	<i>I've been doing this a lot</i>	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4	L7o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7q.
r.	I've been learning to live with the possibility that I have an altered gene.	1	2	3	4	L7r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7s.
t.	I've been praying or meditating.	1	2	3	4	L7t.
u.	I've been making fun of the situation.	1	2	3	4	L7u.

The following items are to be answered only by those women who are married or living with a partner.

☐ If not married or living with a partner skip to the Mood section, next page.

		<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this some</i>	<i>I've been doing this a lot</i>
--	--	---	--	----------------------------------	-----------------------------------

v.	I've been denying or hiding my anger around my spouse/partner.	1	2	3	4	Lv.
w.	I've been denying or hiding my worries around my spouse/partner.	1	2	3	4	Lw.
x.	I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4	Lx.
y.	I've acted more positively around my spouse/partner than I feel.	1	2	3	4	Ly.

MOOD SECTION

1. In the past 6 months, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
- (1) ☐ Yes (5) ☐ No (Skip to Question 2)
- 1a. During this period, did your work or relationships suffer? I12a.
- (1) ☐ Yes (5) ☐ No
- 1b. During this period, did you get counseling or psychotherapy? I12b.
- (1) ☐ Yes (5) ☐ No
- 1c. During this period, did you get medication for this condition? I12c.
- (1) ☐ Yes (5) ☐ No
2. Have you ever in your lifetime had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14
- (1) ☐ Yes (5) ☐ No (Skip to Question 3)
- 2a. During this period, did your work or relationships suffer? I14a.
- (1) ☐ Yes (5) ☐ No
- 2b. During this period, did you get counseling or psychotherapy? I14b.
- (1) ☐ Yes (5) ☐ No

2c. During this period, did you get medication for this condition?

(1) ☐ Yes (5) ☐ No

I14c.

3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems?

(1) ☐ Yes (5) ☐ No

I13.

Symptoms of Strain Section

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.

18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

Relationships Section

1. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.
 (1) ☐ Yes (5) ☐ No

Please complete the following questions if you are married or living with a partner. If you are not married or living with a partner, please check the box and skip to the Background Information Section, page18.

Not married or living with a partner ☐

2. Can you share your most private feelings with your spouse without holding back? C21a.
 (1) ☐ Yes (5) ☐ No
3. Is there anyone besides your spouse with whom you can share your most private feelings without holding back? C21b.
 (1) ☐ Yes (5) ☐ No

Next, we would like to ask you some questions about your spouse/partner's involvement in your health care.

		Never Very Often					
4.	To what extent does your spouse/partner go with you to your appointment with doctors?	1	2	3	4	5	H35a.

5.	To what extent does your spouse/partner talk with your doctor or other medical personnel to assist you in your health care?	1	2	3	4	5	H35b.
6.	To what extent does your spouse/partner keep track of what you need to do about your risk of breast cancer?	1	2	3	4	5	H35c.
7.	To what extent does your spouse/partner change their activities to assist you in your health care?	1	2	3	4	5	H35d.

8. Did your spouse/partner attend individual, family or group sessions to become informed about your risk for breast cancer and what can be done? H36.

(1) ☐ Yes (5) ☐ No

9. How much contact did your spouse/partner have with medical personnel concerning your risk for breast cancer and what can be done about it?

Very Little Or None						A Lot
1	2	3	4	5	6	7

H37.

10. Do you feel your spouse/partner is adequately informed concerning your risk for breast cancer and what can be done about it?

Not at All						Very Much
1	2	3	4	5	6	7

H38.

11. To what extent are you satisfied with your spouse's/partner's involvement in your health care?

Not at All						Very Much
1	2	3	4	5	6	7

H39.

12. How much have you discussed results of your genetic testing with your spouse/partner? B104a.

Not at All	Very Little	Some	A Lot
1	2	3	4

13. When you have these discussions, who generally initiates them?

B104b.

You	Your Spouse	Equally	Not Applicable
1	2	3	-8

14. How satisfied are you with these discussions?

B104c.

Not at All	A Little	Somewhat	A Great Deal	Not Applicable
1	2	3	4	-8

Finally, we would like to ask you some questions about your marriage.

15. Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH.**

		<i>Always Disagree</i>	<i>Almost Always Disagree</i>	<i>Frequently Disagree</i>	<i>Occasionally Disagree</i>	<i>Almost Always Agree</i>	<i>Always Agree</i>	
a.	Religious matters	1	2	3	4	5	6	H3.
b.	Demonstration of affection	1	2	3	4	5	6	H4.
c.	Sex relations	1	2	3	4	5	6	H6.
d.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	H7.
e.	Making major decisions	1	2	3	4	5	6	H12.
f.	Career decisions	1	2	3	4	5	6	H15.

		<i>Never</i>	<i>Rarely</i>	<i>Occasionally</i>	<i>More often than most</i>	<i>Most of the time</i>	<i>All of the time</i>	
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
17.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.

18.	How often do you and your partner quarrel?	1	2	3	4	5	6
19.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6

H21.

H22.

		<i>None of Them</i>	<i>Very Few of Them</i>	<i>Some of Them</i>	<i>Most of Them</i>	<i>All of Them</i>
20.	To what extent do you and your spouse/partner share interests together?	1	2	3	4	5

H24.

How often would you say the following events occur between you and your spouse/partner?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
21.	Have a stimulating exchange of ideas	1	2	3	4	5	6
22.	Calmly discuss something	1	2	3	4	5	6
23.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

24. Considering **only the positive feelings** you have towards your wife/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

H33.

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

15. Considering **only the negative feelings** you have towards your wife/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

Background Information Section

1. Date of Birth _____Month _____Day _____Year

A1.

2. Ethnic Background: White ☐ 1 Black ☐ 4

A2.

- Hispanic ☐ 2 Asian ☐ 5
Native American ☐ 3 Other ☐ 6
3. Religion: Catholic ☐ 1 Protestant ☐ 4 **A3.**
Jewish ☐ 2 Buddhist ☐ 5
Muslim ☐ 3 Other ☐ 6
None ☐ 7
- 3a. How often do you attend religious services? **A3a.**
☐ 1 Less Than Once a Month ☐ 5 A Few Times A Month or More
- 3b. How important are religious and spiritual beliefs in your life? **A3b.**
Not at All Very Important
1 2 3 4 5
4. Are you currently (please check one)? **A4.**
1 ☐ Single 4 ☐ Separated
2 ☐ Married 5 ☐ Divorced
3 ☐ Not married, but living in a steady, marriage-like relationship 6 ☐ Widowed
5. If you are **currently married**, what was the date of your current marriage? **A5.**
(Month/ Year) _____
- 5a. Is this your first marriage? (1) ☐ Yes (5) ☐ No **A5a.**
6. How many children do you have? _____ **A6.**
6a. Number of children living at home? _____ **A6a.**
6b. Number who are under age 6? _____ **A6b.**
6c. Number of Daughters? _____ **A6c.**
7. Do you plan to have more children? (1) ☐ Yes (5) ☐ No (3) ☐ Undecided **A12.**
7a. If **yes**, how many more children? _____ **A12a.**
8. Are you currently working for pay outside the home? **A7.**
(1) ☐ Yes (5) ☐ No
9. If **yes**, about how many hours per week are you working for pay? **A8.**
Less than 10 10-20 21-30 31-40 41 or more
☐ ☐ ☐ ☐ ☐
(1) (2) (3) (4) (5)
10. What is the highest level of education you have completed? (Please Check one) **A9.**
1 ☐ Less than 9th grade 5 ☐ Completed college
2 ☐ Dropped out of high school 6 ☐ Some graduate or professional training

- 3 ☐ Completed high school
4 ☐ Some college

- 7 ☐ Completed graduate or professional training

The following two questions are optional, but we hope that you will provide this information.

11. What is your household's total income? (Please Check one)

A 10.

- | | | |
|---|---|--|
| (1) <input type="checkbox"/> Less than \$10,000 | (4) <input type="checkbox"/> \$30,000 to \$39,999 | (7) <input type="checkbox"/> \$60,000 to \$69,999 |
| (2) <input type="checkbox"/> \$10,000 to \$19,999 | (5) <input type="checkbox"/> \$40,000 to \$49,999 | (8) <input type="checkbox"/> Greater than \$69,999 |
| (3) <input type="checkbox"/> \$20,000 to \$29,999 | (6) <input type="checkbox"/> \$50,000 to \$59,999 | |

12. How many people (adults and children) does this income support? _____

A 11.

Thank You Very Much For Your Participation!

-

LONG TERM FOLLOW-UP STUDY

Questionnaire

TODAY'S DATE _____

ID _____

LONGITUDINAL ASSESSMENT--for Men

This is a follow up questionnaire from a joint project being conducted by the University of Michigan Medical Center and the University of Pennsylvania Cancer Center. It is for people who have received results of genetic testing for an altered gene associated with risk of breast and ovarian cancer. As genetic testing becomes more routine, it is important for us to know how this information affects people's quality of life and future health care decisions. Thank you very much for your participation!

Genetic Testing Section

1. When did you receive your results of genetic testing? **B101.**
(Month/Year) _____

2. Did you encourage your relatives to be tested for BRCA1/BRCA2 before you obtained your results? **B102h.**
(1) ☐ Yes (5) ☐ No

3. Did you discourage your relatives from being tested for BRCA1/BRCA2 before you obtained your results? **B102i.**
(1) ☐ Yes (5) ☐ No

4. Please rate the extent to which each of the following were your reasons for getting your results.

		<div>Not at all</div> <div>Very Much So</div>					
		1	2	3	4	5	
a.	To plan for the future.	1	2	3	4	5	B16b1.
b.	To reduce the uncertainty.	1	2	3	4	5	B16b2.
c.	To make decisions about family planning.	1	2	3	4	5	B16b5.
d.	To find out the risk that may be transmitted to my children.	1	2	3	4	5	B16b6.
e.	Family members wanted me to get testing.	1	2	3	4	5	B16b7.
f.	Other (describe) _____	1	2	3	4	5	B16b8.

5. Before getting your test results, how distressing had it been for you to know that your family may be at increased risk for breast cancer because of your family history?

Not At All Distressing				Very Distressing
1	2	3	4	5

B66b.

6. How distressed **did you expect to be** when you were told you have an altered BRCA1/BRCA2 gene (before you received results)?

Not At All Distressed				Very Distressed
1	2	3	4	5

B68b.

7. How distressed were you when you were told that you had an altered BRCA1 (or BRCA2) gene?

Not At All Distressed				Very Distressed
1	2	3	4	5

B69b.

8. Overall, do you regret the decision to obtain your results?

Not At All				Very Much So
1	2	3	4	5

B71a.

9. When you received your results, what were your immediate reactions?

		Not At All					Very Much So
		1	2	3	4	5	
a.	I felt relieved about being more certain.	1	2	3	4	5	B82a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	B82b.
c.	I did not believe the results.	1	2	3	4	5	B82c.
d.	I felt guilty.	1	2	3	4	5	B82d.
e.	I was depressed.	1	2	3	4	5	B82e.
f.	I worried about the future.	1	2	3	4	5	B82f.

		Not At All				Very Much So		
		1	2	3	4	5		
g.	I thought I would just fall apart emotionally.							B82g.
h.	I felt anxious.							B82h.
i.	I felt angry.							B82i.

10. We are interested in things that people do after being notified of their test results. *After* obtaining your results, which options are you now considering? Please circle one response.

		Definitely Will NOT Do	Probably Will NOT Do	Probably Will Do	Definitely Will Do	Done After Obtaining Results	Does Not Apply to Me	
a.	Encouraging my relatives to be tested	1	2	3	4	5	-9	B103f.
b.	Discouraging my relatives from being tested	1	2	3	4	5	-9	B103g.
c.	Telling some of my relatives what my results were	1	2	3	4	5	-9	B103h.
d.	Not telling some of my relatives what my results were	1	2	3	4	5	-9	B103i.

11. Do you feel you were adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer **before getting your results?**

Not At All						Very Much		
1	2	3	4	5	6	7		B44a.

12. Do you feel you are adequately informed about what it would mean for your children that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much		
1	2	3	4	5	6	7		B47a.

13. How confident are you that **you** will cope effectively with the finding that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48e.

14. How confident are you that **your family members** will cope effectively with the finding that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48f.

15. How much have you discussed results of your genetic testing with female relatives **other than** your spouse/partner?

B105a.

Not at All	Very Little	Some	A Lot
1	2	3	4

16. When you have these discussions, who generally initiates them?

B105b.

You	Your Relatives	Equally
1	2	3

17. How satisfied are you with these discussions?

B105c.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

Personal Attitudes Section

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

2. Now, we would like to ask you some questions about your concerns of breast cancer in your family?

		<i>Not At All</i>		<i>All The Time</i>			
C1.	How often do you worry about your relatives developing breast cancer?	1	2	3	4	5	B32.
C2.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B33.
C3.	How often do you worry about your relatives having an altered gene associated with risk for breast cancer?	1	2	3	4	5	B34.
C4.	To what extent do these worries about interfere with your every day life?	1	2	3	4	5	B35.

Coping Section

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your knowing that you have an altered gene which increases the risk of breast cancer. For each of the statements below, indicate the degree to which your life has been affected positively by your finding you have an altered gene.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that goes with knowing you have an altered gene associated with increased risk for breast cancer. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this some</i>	<i>I've been doing this a lot</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4	L7h.

		<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this some</i>	<i>I've been doing this a lot</i>	
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4	L7o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7q.
r.	I've been learning to live with the possibility that I have an altered gene.	1	2	3	4	L7r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7s.
t.	I've been praying or meditating.	1	2	3	4	L7t.
u.	I've been making fun of the situation.	1	2	3	4	L7u.

The following items are to be answered only by those women who are married or living with a partner.

☐ If not married or living with a partner skip to the Mood section, directly below.

		<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this some</i>	<i>I've been doing this a lot</i>	
v.	I've been denying or hiding my anger around my spouse/partner.	1	2	3	4	L v.
w.	I've been denying or hiding my worries around my spouse/partner.	1	2	3	4	L w.
x.	I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4	L x.
y.	I've acted more positive around my spouse/partner than I feel.	1	2	3	4	L y.

MOOD SECTION

1. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? (1) ☐ Yes (5) ☐ No (Skip to Question 2) I12.
 - 1a. If there was such a two-week period in the **past 6 months**, did your work or relationships suffer? I12a.
(1) ☐ Yes (5) ☐ No
 - 1b. If there was such a two-week period in the **past 6 months**, did you get counseling or psychotherapy? I12b.
(1) ☐ Yes (5) ☐ No
 - 1c. If there was such a two-week period in the **past 6 months**, did you get medication for this condition? I12c.
(1) ☐ Yes (5) ☐ No
2. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? (1) ☐ Yes (5) ☐ No (Skip to Question 3, next page) I14
 - 2a. If there was such a two-week period, did your work or relationships suffer? I14a.
(1) ☐ Yes (5) ☐ No
 - 2b. If there was such a two-week period, did you get counseling or psychotherapy? I14b.
(1) ☐ Yes (5) ☐ No
 - 2c. If there was such a two-week period, did you get medication for this condition? I14c.
(1) ☐ Yes (5) ☐ No
3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems? I13.
(1) ☐ Yes (5) ☐ No

Symptoms of Strain Section

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

Relationships Section

1. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.
(1) ☐ Yes (5) ☐ No

Please complete the following questions only if you are married or living with a partner. If you are not married or living with a partner, please check the box and skip to Background Information Section on page 14.

Not married or living with a partner ☐

2. If married, can you share your most private feelings with your spouse without holding back? C21a.
(1) ☐ Yes (5) ☐ No
3. If married, is there anyone besides your spouse with whom you can share your most private feelings without holding back? C21b.
(1) ☐ Yes (5) ☐ No

First, we would like to ask you some questions about your spouse/partner's involvement in your health care.

4. Did your spouse/partner attend individual, family or group sessions to become informed about your risk for breast cancer and what can be done? H36.
Yes (1) ☐ No (5) ☐
5. How much contact did your spouse/partner have with medical personnel concerning your family's risk for breast cancer and what can be done about it? H37.
- | | | | | | | |
|------------------------|---|---|---|---|---|-------|
| Very Little
or None | | | | | | A Lot |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
6. Do you feel your spouse/partner is adequately informed concerning your family's risk for breast cancer and what can be done about it? H38.
- | | | | | | | |
|------------|---|---|---|---|---|-----------|
| Not at All | | | | | | Very Much |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

7. To what extent are you satisfied with your spouse's/partner's involvement in your health care? H39.

Not at All Very Much
1 2 3 4 5 6 7

8. How much have you discussed results of your genetic testing with your spouse/partner? B104a.

Not at All	Very Little	Some	A Lot
1	2	3	4

9. When you have these discussions, who generally initiates them? B104b.

You	Your Spouse	Equally
1	2	3

10. How satisfied are you with these discussions? B104c.

Not at All	A Little	Somewhat	A Great Deal
1	2	3	4

Second, we would like to ask you some questions about your marriage.

11. Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your spouse/partner **DURING THE PAST MONTH.**

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occasionally Disagree</i>	<i>Frequently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>
a.	Religious matters	1	2	3	4	5	6
b.	Demonstration of affection	1	2	3	4	5	6
c.	Sex relations	1	2	3	4	5	6
d.	Conventionality (correct or proper behavior)	1	2	3	4	5	6
e.	Making major decisions	1	2	3	4	5	6
f.	Career decisions	1	2	3	4	5	6

H3.

H4.

H6.

H7.

H12.

H15.

		<i>All of the time</i>	<i>Most of the time</i>	<i>More often than most</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>
12.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6
13.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6
14.	How often do you and your partner quarrel?	1	2	3	4	5	6
15.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6

H16.

H20.

H21.

H22.

		<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>
16.	Do you and your spouse/partner engage in outside interests together?	1	2	3	4	5

H24.

How often would you say the following events occur between you and your spouse/partner?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
17.	Have a stimulating exchange of ideas	1	2	3	4	5	6
18.	Calmly discuss something	1	2	3	4	5	6
19.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

20. Considering **only the positive feelings** you have towards your spouse/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

H33.

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

21. Considering **only the negative feelings** you have towards your spouse/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

Background Information Section

1. Date of Birth _____Month _____Day _____Year A1.

2. Ethnic Background: White ☐ 1 Black ☐ 4 A2.
- Hispanic ☐ 2 Asian ☐ 5
- Native American ☐ 3 Other ☐ 6

3. Religion: Catholic ☐ 1 Protestant ☐ 4
Jewish ☐ 2 Buddhist ☐ 5
Muslim ☐ 3 Other ☐ 6
None ☐ 7

- 3a. How often do you attend religious services? A3a.

- ☐ 1 Less Than Once a Month ☐ 5 A Few Times A Month or More

- 3b. How important are religious and spiritual beliefs in your life? A3b.

- | | | | | | |
|------------|---|---|---|---|----------------|
| Not at All | | | | | Very Important |
| 1 | 2 | 3 | 4 | 5 | |

4. Are you currently (please check one)?
- | | |
|---|--------------------------------------|
| 1 <input type="checkbox"/> Single | 4 <input type="checkbox"/> Separated |
| 2 <input type="checkbox"/> Married | 5 <input type="checkbox"/> Divorced |
| 3 <input type="checkbox"/> Not married, but living in a steady,
marriage-like relationship | 6 <input type="checkbox"/> Widowed |

5. If you **are** currently married, what was the date of your current marriage? A 5.
(Month/ Year) _____

- 5a. Is this your first marriage? (1) ☐ Yes (5) ☐ No A5a.

6. How many children do you have? _____ **A 6.**

- 6a. Number of children living at home? _____ A 6a.

- 6b. Number who are under age 6? _____ A6b.

- 6c. Number of Daughters? _____ A6c.

7. Do you plan to have more children? (1) ☐ Yes (5) ☐ No (3) ☐ Undecided A12.
 7a. If yes, how many more children? _____ A12a.
8. Are you currently working for pay outside the home? A7.
 (1) ☐ Yes (5) ☐ No
9. If yes, about how many hours per week are you working for pay? A8.

Less than 10	10-20	21-30	31-40	41 or more
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(1)	(2)	(3)	(4)	(5)
10. What is the highest level of education you have completed? (Please Check one) A9.
- | | |
|---|--|
| 1 <input type="checkbox"/> Less than 9th grade | 5 <input type="checkbox"/> Completed college |
| 2 <input type="checkbox"/> Dropped out of high school | 6 <input type="checkbox"/> Some graduate or professional training |
| 3 <input type="checkbox"/> Completed high school | 7 <input type="checkbox"/> Completed graduate or professional training |
| 4 <input type="checkbox"/> Some college | |

The following two questions are optional, but we hope that you will provide this information.

11. What is your household's total income? (Please Check one) A10.
- | | | |
|---|---|--|
| (1) <input type="checkbox"/> Less than \$10,000 | (4) <input type="checkbox"/> \$30,000 to \$39,999 | (7) <input type="checkbox"/> \$60,000 to \$69,999 |
| (2) <input type="checkbox"/> \$10,000 to \$19,999 | (5) <input type="checkbox"/> \$40,000 to \$49,999 | (8) <input type="checkbox"/> Greater than \$69,999 |
| (3) <input type="checkbox"/> \$20,000 to \$29,999 | (6) <input type="checkbox"/> \$50,000 to \$59,999 | |
12. How many people (adults and children) does this income support? _____ A11.

Thank You Very Much For Your Participation!